Digital Strategies for Returning Value to Research Participants

Elizabeth Cope, Rachel Dungan, Priya Govil, and the PDRC LN Digital Engagement Workgroup
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INTRODUCTION

Growth of Patient-/Participant-Driven Research

The past decade has seen increasing recognition that the traditional medical and health services research enterprise is not driving improved care delivery and health outcomes to the degree it could or should be. All too often, research questions are not well-aligned with the most pressing needs of patients and those that care for them. The ability to draw meaningful inferences often suffers from challenges tied to participant recruitment and retention as well as the analysis of incomplete data. Moreover, traditional means and methods of communicating research findings are not optimized to reach the audiences who can ensure the evidence is utilized to inform healthcare decisions. The result is a research enterprise that is inefficient, costly, and insufficiently impactful. 1

A key strategy to help the research enterprise course correct has been the engagement of patient and stakeholder partners in the research process. It is postulated that by involving patients and other end-users of research throughout the complete life cycle—from question identification through design and conduct to analysis and dissemination—researchers can ensure that results are relevant, complete, ready for implementation, and trusted by key individuals and communities.2 As patient-driven and patient-engaged research activities become more common, new entities are being established to provide much-needed backbone support for more sustainable, substantive collaborative relationships. So called patient-/participant-driven research communities (PDRCs) are joining the research landscape to accelerate transformation toward an enterprise better equipped to meet the needs of patients and their caregivers. Governed by patients and other stakeholders, PDRCs aim to improve the relevance, rigor, and speed of health research. In addition to their health research portfolios, these organizations and communities are also making important contributions to the field of engagement science—the body of inquiry dedicated to understanding the dynamics driving successful multi-stakeholder engagement in research as well as the influence and impact of engagement on research. The report contained herein represents one such contribution from a recently formed PDRC Learning Network (LN).

PDRC Learning Network

In August 2019, the Patient-Centered Outcomes Research Institute (PCORI) partnered with NORC at the University of Chicago (NORC) and AcademyHealth to convene the PDRC LN with the objective of building capacity and promoting sustainability of PDRCs as an emergent fixture of the health research enterprise. Major activities of this initiative include:

- Facilitating a community of learning across eight PDRCs funded by PCORI;
- Conducting an environmental scan and characterization of the broader PDRC landscape to understand their role, needs, and barriers/facilitators of success;
- Contributing to the national discussion on the role of PDRCs through dissemination of lessons learned.

To support learning among the PDRCs, the PDRC LN provides multiple avenues for members to share breakthroughs and successes, navigate challenges, learn from external experts in the field, and workshop joint solutions. As part of these efforts, the PDRC LN has established three workgroups focused on priority topics identified by the PDRCs. The three workgroups and their focus areas include:

- Digital Engagement: improving the effectiveness of strategies for digitally-based engagement with patients and other stakeholders;
- Improving Representativeness: improving the diversity and representativeness of patient representation in research networks, research studies, and governance structures;
- Sustainability: identifying successful value propositions, marketing strategies, and business models to foster the sustainability of PDRCs.

In addition to facilitating learning and communication among PDRC LN members, workgroup activities are designed to generate generalizable findings. Participating PDRCs collaborate to produce tangible outputs that can enhance the work of PDRC LN members and advance the field of engagement science.

Digital Engagement Workgroup Case Study Series

This case study series is the first product developed by the Digital Engagement Workgroup (DEWG); it reflects work completed over a period of eight months by a group of six participating PDRCs along with PDRC LN staff (Table 1). Following initial discussions to identify topics of shared priority, the DEWG decided to focus on the issue of using digital strategies to return value to participants. This topic speaks to two key challenges all participating members face in common: (1) community participant retention and (2) delivering value to patients and their families. Prior to embarking on a joint strategy to address this challenge, the DEWG sought to understand the existing landscape of approaches. Accordingly, the following report is designed to provide:

- A clear definition of the challenge;
- A scan of existing approaches from the published literature and other sources;
- A series of in-depth examples from prior and ongoing work among the DEWG members;
- A set of guiding principles emerging from the field.

Digital Strategies for Returning Value to Research Participants
This report is intended to serve as a resource for the participating members of the DEWG and PDRC LN as well as professionals operating in the broader patient-/participant-driven research landscape. The goal is to advance the collective understanding regarding how to think about value in the context of research participation, and the underlying principles that should guide strategies for its delivery when using digitally-based methods.

Table 1. Digital Engagement Workgroup (DEWG) membership.

<table>
<thead>
<tr>
<th>DEWG MEMBER</th>
<th>MEMBER PDRC</th>
<th>POPULATION OF FOCUS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sue Friedman</td>
<td>ABOUT</td>
<td>People affected by breast, ovarian, and other hereditary cancers</td>
</tr>
<tr>
<td>Vinny Malanga Cara Pasquale</td>
<td>COPD-PPRN</td>
<td>People affected by chronic obstructive pulmonary disease (COPD) and other related disorders</td>
</tr>
<tr>
<td>Emily Cerciello Laura Weisbein</td>
<td>IBD Partners</td>
<td>Patients, researchers, health care providers, and other stakeholders affected by inflammatory bowel disease (IBD)</td>
</tr>
<tr>
<td>Kate Harrow Melissa Mock</td>
<td>ImproveCareNow</td>
<td>Children with Crohn’s Disease or ulcerative colitis and related stakeholders</td>
</tr>
<tr>
<td>Renee Leverty Marc Natter Meg Waite</td>
<td>PARTNERS</td>
<td>Children with juvenile idiopathic arthritis (JIA), childhood-onset systemic lupus erythematosus (lupus), and juvenile dermatomyositis (JDM); their family members; and other key stakeholders</td>
</tr>
<tr>
<td>Michael Lubensky Mitchel Lunn Juno Obedin-Maliver</td>
<td>PRIDenet</td>
<td>Sexual and gender minorities (SGM)</td>
</tr>
<tr>
<td>Rebekah Angove Katherine Browne Elizabeth Cope Prashila Dullabh Rachel Dungan Priya Govil Lorraine Johnson</td>
<td>PDRC LN</td>
<td>PDRC Learning Network membership: eight PCORI-funded PDRC engagement awardees (EAs)</td>
</tr>
</tbody>
</table>
RETURNING VALUE TO PARTICIPANTS
Foundations and Implications of Research Engagement

Primary data collection is a cornerstone of clinical and health services research, particularly when it involves intervention assignment and/or the assessment of patient-reported data. The inability to recruit and retain the required participants in a research study can have serious implications for both the internal and external validity of the project. Indeed, most trials fail to reach their recruitment goals. Roughly 86% of clinical trials fail to meet enrollment timelines, with 18% or more failing due to recruitment issues. It can result in a study that is underpowered, vulnerable to several forms of bias, or unable to generalize its findings. For example, while evidence suggests that an attrition rate over 20% warrants concern related to the possible introduction of bias, studies also indicate that losing even 5% of the study sample can be problematic. Hardly a rare problem, attrition (at rates exceeding 7%) affects a majority of health research studies. Moreover, poor research participation can lead to premature study closure or the need to extend recruitment periods, in turn increasing costs and workload. All of this ultimately translates into gaps and delays in the discovery, dissemination, and implementation of effective interventions.

We conceptualize the drivers of research participation (including recruitment and retention) using an adaptation of the framework presented by Brown and Topcu (2003). The framework combines aspects of the theory of reasoned action and the health behavior model, and is presented in Figure 1. The framework shows research participation as being preceded by a person’s willingness to take part (behavioral intention), which is itself determined by the interplay of predisposing factors, enabling resources, and illness need factors.

- **Predisposing factors**: These include certain demographic and sociocultural factors. Notably this includes attitudes, beliefs, and perceived norms about research and health care; trust and prior experience with research/health care; sense of personal agency; as well as education and health literacy.

- **Enabling resources**: These factors consist of resources that facilitate participation in research. Most prominently, they include resources to address awareness, eligibility, accessibility, social support, and a sense of community (or “belongingness”).

- **Illness need**: This is comprised of disease symptomatology and life course as well as an individual’s beliefs about the disease and perceptions of its severity. It also includes perceived need and benefit of participation in research for themselves as well as their family members.

Finally, the framework also acknowledges the role of broader contextual factors related to the health care system, its organization, policies, and resources, as well as physical and sociocultural environmental factors as determinants of research participation. This includes the goals and priorities of industry (which are sometimes at odds with patient groups/priorities) and funding agencies. Taken together, the many factors included in this framework differentially predict participation in research, and their effects differ by race/ethnicity, socioeconomic status, and other characteristics. In developing effective recruitment, retention, and other engagement tactics, it is useful to consider which factors are most prominent and potentially modifiable in the target audience and then build protocols to act on those factors. In the next section, we explore the concept of returning value as one overarching strategy capable of addressing multiple determinants captured in this framework.

**Figure 1. Conceptual framework for predicting research participation (adapted from Brown and Topcu [2003]).**
Digital Strategies for Returning Value to Research Participants

Why Return Value
A defining feature of research participation is its voluntary nature. Strict ethical guidelines are in place to ensure researchers do not coerce individuals into participation, and researchers do not possess the ability to mandate participation. And yet, too often the needs and motives of just one party in the researcher-participant relationship are seen as important: the needs of the researcher to complete the study. Informed consent forms routinely cite no direct benefit beyond the possibility that participation may contribute to discovery of effective interventions that will help patients in the future. While attention has been given to the provision of incentives to participate, these often translate into modest financial payments—substantive enough to compensate for time spent participating but small enough so as not to be coercive, and often too small to offset the true costs of participation (travel, lost wages, parking, etc.).

This relationship contrasts with researchers’ approach to nearly any other commonly cultivated relationship, where two-way exchanges predominate. For example, relations with staff are characterized not only by the work the staff contributes to the study, but also by what the researcher provides the staff (salaries, benefits, professional development, etc.). Similarly, relations with other scientific investigators involve mutually beneficial arrangements in terms of co-authored publications, career advancement, and the like. Funders receive scientific products that help advance their agendas and strategic plans in turn for resourcing the researcher’s study. Thus, only participants are treated as though their need in the relationship with a researcher is roughly equivalent to the researcher’s own needs (i.e., the participant needs nothing in return beyond the satisfaction of having helped the researcher complete the study). Compounding this is the fact that, in many cases, participants never learn how their contributions actually supported the study.

Productive and lasting relationships of any type are built when individuals and organizations seek to understand and meet the needs of the partner, whether that partner is a funder, collaborator, staff person, or volunteer participant and their community. The return of value to participants can thus initiate a virtuous and mutually-beneficial cycle of research engagement that improves recruitment of value to participants can thus initiate a virtuous and mutually-beneficial cycle of research engagement that improves recruitment and retention, builds trust, and strengthens the broader research enterprise. As noted in the previous section, research participation is multifaceted. Participants may volunteer for a multitude of reasons and with various expectations for the return on their investment of energy, time, personal information, and acceptance of risk. As such, in seeking to return value to engaged participants, researchers should consider the distinctive goals, needs, preferences, and barriers of their participants. For some, financial compensation might suffice as compensation or acknowledgement of value; for others, however, the return may need to take a more social or intellectual form in order to be seen as a meaningful return on investment. Beyond illustrating appreciation for participants’ contributions, the cycle of returned value helps to reinforce relationships by acknowledging the dignity of participants. The gesture further helps to establish the trustworthiness of researchers, and the credibility of a research enterprise committed to the conduct of research that can inform real-world policy and practice to improve health outcomes. In this way, it is possible to envision the return of value as establishing a feedback loop with elements of each of the major drivers of willingness to participate: predisposing factors, enabling resources, and illness need. In the next section, we explore potential approaches for returning value, electing to exclude the more traditional tokenistic forms of research incentives.

Approaches to Returning Value
Many study participants report having enrolled in research activities as a reflection of altruism, academic or personal interest, commitment to volunteerism, or a desire to “share in the scientific process.” In the case of hereditary conditions, individuals may also be motivated to participate to help relatives and family members. It is perhaps unsurprising then that most discussions related to returning value to date have centered on providing study participants with research results. Indeed, study participants have noted an interest in receiving results, and there is growing recognition among researchers that returning results to participants is important and helps to honor their contribution to the scientific process. Below, we review the debates over returning results to participants and then consider additional avenues for providing value in the context of research studies.

Return of Results
The return of research results can take two major forms. First, attention has been given to the return of de-identified, aggregate study findings through channels beyond peer-reviewed publications. Focus is typically on developing results summaries that are tailored to specific target audiences to deliver key messages in a format that is accessible, prioritizes content of most relevance and interest, and is easily digestible. Value stems from seeing the fruits of one’s contributions to the research study and understanding its connections to the broader evidence base as well as its relevance to the real-world questions of interest to patients and providers. This can generate a feedback loop, helping to improve the participant’s education on topics related to the condition under study and the research process in general, enhance self-efficacy, and build trust in the research enterprise. Despite alignment with normative principles, such as empowerment and co-learning, known interest among study participants, and recognition among researchers that participants would find this valuable, evidence suggests researchers often do not pursue the return of aggregate results—and this is especially true when results are null. Barriers cited include concerns about health literacy and the logistical challenges related to time, resources, and capacity to disseminate effectively to these audiences.

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The second form of returning results is that of returning individual research results. This involves reporting back to the participant the results of his/her/their own data contributions—survey results, test results, unblinding after the study is completed, etc. Results may be contextualized by including comparisons with the study-wide average or distribution, or presented on their own. For example, many patient-driven registries include gamification, where the participant immediately sees how they compare with other patients in the registry. This topic has seen considerably more debate as it raises a number of additional issues not present with the return of aggregate findings. From an ethical perspective, returning results promotes the principles of autonomy, justice, and beneficence. From a practical standpoint, there is evidence that it improves recruitment/retention and helps patient communities better connect and work with investigators. Value is generated by providing the participant with additional information about his/her/their own person and/or condition, and by inviting participants to become scientific collaborators—building trust in the process. Moreover, this practice may be especially valued by participants whose clinical decision-making can be directly informed by such results, targeting both illness need factors as well as predisposing factors such as self-efficacy. One evaluation of participants' perceptions of research experiences found that, "Participants consistently expressed disappointment if they did not receive test results during or after a study." Beyond personal health-related reasons, participants also reported linking the return of overall study findings, "...to their feelings of being valued," because it acknowledged their desire to "...share broadly in the new knowledge that comes both from their participation in the study as well as from the overall study."  

The barriers to returning individual results include but extend beyond those cited for the return of aggregate results. Of particular concern to researchers, some tests used for research purposes may not have the same degree of validity found in tests for clinical care and reports back to participants may not include sufficient information to contextualize the results. There is potential for feelings of undue stress or even the pursuit of unwarranted medical interventions among patients and caregivers—which could prove costly or burdensome. Relatedly, there are also concerns about how this might encourage the conflation of research and care, two separate enterprises which necessarily have very different objectives and priorities. Finally, given the need to provide proper contextualizing information and deliver the results in a format that is readily accessible to participants, a more practical barrier is the potential for increased costs to the research enterprise in terms of time, resources, and expertise to support this type of dissemination. The time needed to personalize reports to highlight key findings quickly scales with study enrollment, and providing accessible context requires specific communication skills.

A recent report by the National Academies of Sciences, Engineering, and Medicine (NASEM) reviewed the current evidence on benefits, harms, and costs of returning individual results. It concluded that while there are compelling reasons to return individual results under certain circumstances, there are other times when it is appropriate to limit or constrain the return of results. As a result, the committee recommended the determination be made on a case-by-case basis balancing ethical principles and the specific context of the situation. However, it did note in particular that in the interest of reciprocity, respect, transparency, and trust, the return of results should be routinely considered and built into the design of research protocols involving human participants.

Additional Avenues for Returning Value

Beyond the return of results, researchers have recently been encouraged to explore broader definitions of "value" that account for the unique experiences and perspectives of study participants. For example, research participants also report placing high value on experiences or resources that:

- increase awareness of the ways genetic / lifestyle factors influence their health;
- contextualize their health outcomes or behaviors relative to norms;
- provide information about studies in progress, or for which they may be eligible;
- offer opportunities to engage in the research process as collaborators or partners;
- facilitate connection with others who may have shared characteristics or experiences;
- build new skills or capacities.

Recognizing that participants may appreciate these types of benefits and resources, researchers might consider creating research environments conducive to fostering value-laden relationships or hosting value-rich experiences. While they do not include the return of study results to participants, the strategies noted above can make important contributions to a virtuous circle of engagement by addressing a host of illness need, predisposing, and enabling factors such as improved understanding of one's own condition, improved health literacy, enhanced self-efficacy, strengthened social support, increased trust in the research enterprise, and increased access to new research participation opportunities. In combination with returning results, and particularly in circumstances when return of results is not appropriate, researchers should build these and other strategies into their protocols to ensure participants are not only incentivized but they receive real, tangible benefit from their contributions to the study. Normalizing this substantive acknowledgment of the participant's essential and uniquely valuable contribution to the research enterprise could help alleviate the widespread engagement challenges currently impacting health research.
**OPPORTUNITIES PRESENTED BY DIGITAL ENGAGEMENT**

Digital tools and methods can directly address some practical barriers to engagement by mitigating limitations related to cost and scale. They offer additional promise by enhancing or enabling the return of value to research partners and participants. Digital tools may offer a more dynamic or interactive means for providing condition- or person-specific information, in ways that address patients’ illness needs. Such tools and platforms may also serve as enabling resources that facilitate participation or engagement by offering flexible, tailored, or convenient channels for contribution. Finally, digitally-enabled solutions can be used to cultivate communities—enhancing trust and communication between patients, researchers, and ultimately the broader research enterprise. In these and other ways, increased use of digital tools and methods can bolster the research community’s adoption of a new, mutually-beneficial approach to researcher-participant relationships. To determine how such tools and methods are already being used in the field, the team conducted a semi-systematic scan of peer-reviewed and gray literature. The methods and findings are described below.

**Scan Methods**

The purpose of the digital engagement scan was to identify how digital tools are currently being used to return value to research participants in the health research sphere. The scan, limited to publicly available tool descriptions found in the peer-reviewed and gray literature or on websites, provides a foundation for the deeper exploration of DEWG member tools presented in the case studies later in this report.

To identify existing approaches, the scan focused on the following:

- **PCORI Engagement Tool and Resource Repository:** This repository captures engagement-related tools and resources developed and used by PCORI awardees and includes tools of varying maturity that may or may not have been reported in the peer-reviewed literature. The following search string initially produced 85 results:

  "digital" OR "virtual" OR "online" OR "web-based" OR "application"

- **PCORI Engagement in Health Research Literature Explorer:** This searchable database includes a curated selection of peer-reviewed publications on engagement in health research that is updated on a monthly basis leveraging PubMed/MEDLINE searches as well as reviews of relevant journals not yet indexed in PubMed (e.g. Research Involvement and Engagement). Twenty-Three results tagged for “Detailed Description of Engagement in Health Research” were identified by filtering the 73 results originally produced using the following search string:

  "digital tool" OR "digital method" OR "online tool" OR "online platform" OR "online portal" OR "web-based platform" OR "digital application" OR "web-based application") AND ("citizen science" OR "engagement method")

- Additional examples suggested by DEWG members or subject matter experts consulted on an ad hoc basis.

Searches were conducted between April and June, 2020. To be included, tools/resources needed to involve digital approaches to interact with participants (or foster participant interaction with each other) on behalf of a research project/initiative. Given the focus on returning value in research, digital tools/resources were excluded if they focused solely on:

- Study enrollment or consent
- Data collection
- Public dissemination of static content such as aggregate findings from completed studies
- Patient engagement in clinical care
- Resources for training non-participants in the conduct of engaged research

Due to the limited number of tools/resources fitting these criteria, the scan does incorporate a small number of examples from beyond health research (citizen science) to highlight resources in related fields. These examples do not reflect a systematic search of non-health research related digital tools/resources.

**Scan Findings**

The scan resulted in a set of ten examples meeting the inclusion/exclusion criteria outlined above. While the scan provided evidence that researchers are exploring increasingly creative ways to leverage digitally-enabled solutions in their work, the tools and methods identified tended to align with three main functionality types:

1. **Returning results:** individual and/or aggregate results of completed or ongoing studies with contextual information and/or opportunities for participants to engage more deeply with the content (number of scan results = 3).

2. **Building capacity:** training modules to prepare patients to be research participants/partners (number of scan results = 2).
3. **Cultivating community**: creating virtual spaces and/or opportunities for resource/knowledge sharing, communication, and collaboration (number of scan results = 5).

Below, each functionality type is summarized and one scan result is highlighted, outlining the goals of the overarching project or initiative, the goals of the digital tool, key features and functionality of the tool, and the potential value provided to research participants.

**Returning Results**

One of the most fundamental uses of digital tools to return value to research participants, as previously noted, is to support the provision of individual or aggregate results. Digital platforms offer an approach that can scale easily for the creation and distribution of personalized reports that contextualize an individual’s results as part of the broader study or by tying in additional information to aid with interpretation. Such tools can be built into broader participant portals that support a wide range of functionality including enrollment and data collection. One example from the scan is highlighted below. Complete scan findings are presented in Appendix I.

**Digital Exposure Report-Back Interface (DERBI)**

DERBI is a platform that has been used by researchers to return value to participants in environmental health studies funded by the National Institute of Environmental Health Sciences (NIEHS), including: the Personal Exposure Report-Back Ethics (PERE) study, the CDC Green Housing Study (GHS), and the Child Health and Development Study.

<table>
<thead>
<tr>
<th>Table 2. Digital Exposure Report-Back Interface (DERBI)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Project Aim(s)</strong></td>
</tr>
<tr>
<td>- Support return of results to individuals participating in environmental health studies</td>
</tr>
<tr>
<td>- Empower individual action to lower unnecessary exposure to harmful chemicals</td>
</tr>
<tr>
<td><strong>Goal(s) of Tool</strong></td>
</tr>
<tr>
<td>- Present complex chemical exposure data in accessible ways</td>
</tr>
<tr>
<td>- Share individual and aggregate results to enable the participant to compare personal results with those found in the broader research sample</td>
</tr>
<tr>
<td>- Provide participants with guidance on reducing exposure to harmful chemicals</td>
</tr>
<tr>
<td><strong>Key Features &amp; Functions</strong></td>
</tr>
<tr>
<td>- User-centered, interactive design and graphics</td>
</tr>
<tr>
<td>- Digestible, accessible, and personalized results</td>
</tr>
<tr>
<td>- Comparative results analysis</td>
</tr>
<tr>
<td>- Tailored recommendations for lowering harmful exposure</td>
</tr>
<tr>
<td><strong>Returning Value Approach</strong></td>
</tr>
<tr>
<td>- Provides participants with direct access to their individual research results</td>
</tr>
<tr>
<td>- Allows participants to explore the data and see how they compare to other participants</td>
</tr>
<tr>
<td>- Gives participants actionable information on how to change their own exposure to environmental chemicals</td>
</tr>
<tr>
<td>- Enables participants to increase their scientific literacy by including resources to aid in interpretation of research testing and results</td>
</tr>
<tr>
<td><strong>Sources</strong></td>
</tr>
<tr>
<td>1. DERBI: A Digital Method to Help researchers Offer “Right-to-Know” Personal Exposure Results</td>
</tr>
<tr>
<td>2. Digital Exposure Report-Back Interface (DERBI)</td>
</tr>
</tbody>
</table>

This platform seeks to return value by honoring participants’ “right to know” their own results related to harmful chemical exposure. Researchers employed user-centered design to develop the functionality, look, and feel that would be most useful to participants. Features emphasize the ability to compare an individual’s results with distributions across the full study, as well as the provision of complementary educational materials to support participant interpretation of results and risk-modifying actions that could be taken in follow-up.
Building Capacity

The scan also surfaced an example of a tool designed specifically with the aim of building participant capacity (i.e. education/skill-building focus). Digital approaches can be particularly useful in this context by increasing access to valuable educational content, or by presenting that content in interactive and dynamic formats to meet the needs of diverse learners. These types of tools could be used to offer online trainings or educational modules that support self-guided or self-paced learning. The example provided below represents an approach that could be readily implemented in other contexts with limited tailoring to ensure relevance to the target audience/research participant community.

Celiac Disease Foundation Patient Advocate Platform

The Celiac Disease Foundation Patient Advocate Platform centers on a set of training modules to prepare patients and their caregivers for future engagement in the research process as partners or participants. It highlights the unique expertise this community has to offer the research enterprise and focuses on increasing knowledge about celiac disease and clinical research so they can participate as informed and effective patient advocates. As shown in Figure 4, the platform also contains tools to connect potential participants to research opportunities, information about ongoing trials, and a mechanism to join the affiliated patient registry. Here, the return of value includes skills- and capacity-building activities that can help community members better understand the relationship between the research enterprise and their own clinical treatment options or outcomes as well as direct access to opportunities to participate.

Table 3. Celiac Disease Foundation Patient Advocate Platform

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- Increase and improve patient-centered outcomes research and clinical trials related to celiac disease to improve the lives of patients and their caregivers</th>
</tr>
</thead>
</table>
| Goal(s) of Tool | - Educate affected individuals about celiac disease and clinical research, so that they are prepared to participate in research as informed, effective advocates  
| | - Facilitate opportunities for patients to join recruiting research studies and a patient registry related to celiac disease and gluten intolerance  
| | - Inform patients about current clinical trials related to celiac disease and gluten intolerance |
| Key Features & Functions | - Training component includes a baseline assessment, video modules, understanding checks for each module, a final assessment, and a certificate of completion  
| | - Access to information about ongoing and recruiting trials/studies, which includes a responsive trial search engine that can limit to specified parameters (e.g., trials calling only for male participants)  
| | - Access to enroll in iCureCeliac patient registry by setting up a personalized account and submitting survey data |
| Returning Value Approach | - Builds capacity and increases scientific literacy through education about the condition and clinical research  
| | - Invites and empowers patients to engage in the research process as participants |
| Source | 1. Become a Patient Advocate40 |
Digital Strategies for Returning Value to Research Participants

Cultivating Community

Beyond one-way transmission of information in the form of data resources or research results, digital platforms and portals can also support bidirectional exchange within and among researcher and participant communities. Offering shared spaces for communication and collaboration, these Virtual Communities of Practice (VCoPs)35 can provide the scaffolding for meaningful contributions from engaged participants – while also connecting them to others who may share their lived experience. Similarly, such platforms can strengthen relationships between researchers and participants, which instills mutually-beneficial trust and respect. As above, one example from the scan is highlighted below. Complete scan findings are presented in Appendix I.

Open Humans

Open Humans offers a platform that seeks to balance the practical challenges of merging diverse streams of individual-level data with the ethical challenges of mitigating risks associated with sharing personal data. The community-based platform offers resources to accommodate a range of data, such as personal genetic data, wearables, and continuous glucose monitor data, as well as the tools to enable close individual control over personal data access and sharing authorizations. Through additional widgets and tools, the platform seeks to empower individuals to understand and explore their own data as well as providing researchers with the ability to establish new projects.

Table 4. Open Humans Platform

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- To create a digital ecosystem to facilitate individual data aggregation across diverse sources, management of data sharing, and co-creation of research</th>
</tr>
</thead>
</table>
| Goal(s) of Tool | - Enable data sharing and exploration projects at individual and group levels for the purposes of education, health, and research  
- Facilitate de novo data collection as well as data uploads/imports from diverse platforms  
- Foster equal opportunity for data exploration across researchers, patients, data scientists, citizen scientists, and the like |
| Key Features & Functions | - Supports a diverse range of data from external sources (e.g. 23 and Me, AncestryDNA, Fitbit Connection, Google Fit, Quantified Flu)  
- Widgets to support creation of de novo data collection mechanisms  
- Tools and resources (including modest funding) to support new project creation  
- Resources and a community forum to support individuals interested in self-research  
- Slack channel to promote community engagement |
| Returning Value Approach | - Builds capacity and increases scientific literacy through annotated analytic and interpretative tools  
- Empowers users to contribute their own data and tightly control how the data are used and shared  
- Connects users to new and ongoing data exploration projects in which they may be interested in participating  
- Invites participants to take on the role of scientific investigator by participating in citizen science projects or exploring analytical tools on their own  
- Provides equalizing opportunities for users from all backgrounds and experiences to directly lead, partner in, and/or contribute to data exploration projects  
- Builds community and social support by providing mechanisms for users to directly engage with each other and other stakeholders |
| Sources | 1. About Open Humans42  
2. Open Humans: a platform for participant-centered research and personal data exploration43  
3. User Perspectives of a Web-Based Data-Sharing Platform (Open Humans) on Ethical Oversight in Participant-Led Research: Protocol for a Quantitative Study44 |

Figure 4. Screenshots from an Open Humans project landing page.

About Quantified Flu

Can wearable devices help predict when we’re getting sick? Help us find out! We have two ways to you can contribute: analyze past data (we’ll create a graph for you!), and sign up to track your health. Good going forward...

Your data for good. The deidentified & aggregated data will be shared with researchers publicly to maximize the impact of our work. But you can opt-out of this at any time!

<table>
<thead>
<tr>
<th>Project membership</th>
<th>Recent Members</th>
</tr>
</thead>
<tbody>
<tr>
<td>You have not joined Quantified Flu yet.</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Permissions &amp; added data</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Requested permissions:</td>
<td></td>
</tr>
<tr>
<td>Fitbit Connection</td>
<td></td>
</tr>
<tr>
<td>Fitbit App</td>
<td></td>
</tr>
<tr>
<td>On-Demand Health</td>
<td></td>
</tr>
<tr>
<td>Self-reported activities</td>
<td></td>
</tr>
<tr>
<td>Weight data</td>
<td></td>
</tr>
</tbody>
</table>

We have two ways you can contribute...

Report past illness

Report when you get sick and share your wearable device data. We’ll plot your data for you! Currently we support Fitbit & Oura Ring, Apple Watch, Omron, and Google Fit. Ask us for help with your wearable, if this is missing or fat.

Track symptoms going forward

Sign up for daily check-ins to tell us if you get sick, as well as symptoms and viral test results.

Using your data for good

You can opt-in to share the aggregated and deserialized data with researchers and publicly, to maximize the impact of your data. This includes some weeks of wearable data around the sick data, as well as the reported symptoms.

Table 4 . Open Humans Platform

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
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| Sources | 1. About Open Humans42  
2. Open Humans: a platform for participant-centered research and personal data exploration43  
3. User Perspectives of a Web-Based Data-Sharing Platform (Open Humans) on Ethical Oversight in Participant-Led Research: Protocol for a Quantitative Study44 |
Summary
Scan results provided general insights into themes and trends in existing, relevant uses of digital solutions. While returning results to participants is a dominant theme in the literature discussing how to return value to participants, few detailed examples of approaches using digital tools were identified. The category with the most examples was cultivating community. Here, digital platforms that incorporate more complex functionality to enable cross-user interaction and participatory research were most prominent. While these platforms were often designed with a few goals in mind, the amount of value they potentially provide is more diffuse and ranges from capacity-building to connections to resources to empowering as research partners.

It should be noted that this search was subject to several limitations. The scan was limited to only those tools documented in the peer-reviewed health-related research literature or in the PCORI Engagement Tool and Resource Repository. Additional tools would likely be discoverable in the broader citizen science literature, spanning the natural, physical, and engineering sciences. However, it is anticipated that these would share many features with those found in the Zooniverse and NatureNet examples (see Appendix I). Further, these results are likely not an accurate representation of the true volume, breadth, and depth of digital tools being developed in the health research sphere. Oftentimes, tools are developed to facilitate a research project. The results of the project are what get reported in the literature, with limited to no mention of the infrastructure support tools. Anecdotal reports from DEWG members support this conclusion, and some tools mentioned by members were unable to be included in the scan due to the lack of existing publicly available documentation. Finally, even when described in the peer-reviewed literature, tools created for use in research contexts were not always described in detail; studies reporting research results, for example, did not always provide detailed documentation regarding the creation of digital tools, or the rationale behind key design elements. This limited the ability to comprehensively describe core functionality and potential value benefits for participants.

In light of these limitations, the DEWG sought to gain a deeper, more nuanced understanding of the creation and use of emerging tools. The following section includes a series of case studies of participating DEWG members as illustrative examples of ways digital tools or methods are being used to return value and promote engagement.
DEWG MEMBER CASE STUDIES

Introduction
The DEWG member case studies were developed to serve three purposes: (1) to add breadth to the findings from the literature scan by showcasing additional ways research initiatives use digital tools/strategies to return value to participants; (2) to add depth to the findings from the literature scan through descriptions of tool/strategy design and implementation; and (3) to promote sharing of promising practices across members of the PDRC LN. Case studies were developed as a collaborative process between members of the PDRC LN team and representatives from the PDRCs participating in the DEWG. First, the group worked together to develop a discussion guide with the following objectives:

- Collect background information about networks and how they currently engage with participants
- Focus on one particular tool/strategy for returning value to participants that uses digitally-based techniques
  - Understand how networks are defining value and from whose perspective
  - Understand why networks thought their approach would be a good fit for returning value
  - Describe the approach with reasonable detail as well as the experience of developing and/or implementing the approach (depends on maturity of the approach per network)
  - Identify the results of approach design/implementation—what worked/did not work; unintended consequences; places where things could have been done differently
  - Identify broader lessons learned and recommendations for others in the field based on this experience

Next, members of the PDRC LN team used the discussion guide to conduct 90-minute interviews with each PDRC focused on a specific digital tool/strategy for returning value of their choosing. The PDRC LN team then developed narrative summaries of these discussions for PDRC review and revision. The final versions of these narratives were then incorporated into the report in the sections below. Case studies were distributed across two of the three previously identified categories of digital tools for returning value, as outlined in Table 5.

Notably, case studies reflect a mix of custom-built tools and strategies that combine pre-existing digital approaches to deliver value in novel, unique ways. It is also important to note that these case studies provide a curated sample of digital tools/strategies from the participating PDRCs and should not be interpreted as a comprehensive representation of all digital approaches currently in use and/or development by these entities.

Table 5. Digital tools/strategies highlighted in the PDRC case studies, by PDRC and type.

<table>
<thead>
<tr>
<th>PDRC</th>
<th>Tool/Strategy Type</th>
<th>Tool/Strategy Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>ABOUT</td>
<td>Returning results</td>
<td>Research Collaboration Page</td>
</tr>
<tr>
<td>COPD-PPRN</td>
<td>Cultivating community</td>
<td>Bridge Project's Use of COPDF360 Social</td>
</tr>
<tr>
<td>IBD Partners</td>
<td>Cultivating community</td>
<td>Research Ideation &amp; Prioritization Tool</td>
</tr>
<tr>
<td>ImproveCareNow</td>
<td>Cultivating community</td>
<td>Pipeline to Engagement</td>
</tr>
<tr>
<td>PARTNERS</td>
<td>Cultivating community</td>
<td>Web of Engagement App Development Survey</td>
</tr>
<tr>
<td>PRIDEnet</td>
<td>Returning results</td>
<td>Research Dissemination Plan &amp; Auxiliary Tools</td>
</tr>
</tbody>
</table>
Case Studies

ABOUT PPRN: Research Collaboration Page

Case Study Authors: Jessica Conaty, MPH; Marleah Dean, PhD; Sue Friedman, DVM; Kelly Owens, PhD; Diane Rose, BS; Piri Welch, PhD

PDRC LN Contributors: Elizabeth Cope, PhD, MPH; Rachel Dungan, MSSP; Priya Govil

Affiliations:

a. Health Informatics Institute, University of South Florida Morsani College of Medicine, Tampa, FL, USA.

b. FORCE: Facing Our Risk of Cancer Empowered, Tampa, FL, USA.

c. AcademyHealth, Washington, DC, USA.

About the Network. The American BRCA Outcomes and Utilization of Testing (ABOUT) Patient-Powered Research Network (PPRN) arose from a collaboration between Facing our Risk of Cancer Empowered (FORCE), the largest hereditary cancer advocacy group in the United States, and researchers at the University of South Florida Morsani College of Medicine. ABOUT’s purpose is to improve informed decision-making and health outcomes for people affected by hereditary breast, ovarian, and related cancers through the conduct of patient-centered outcomes research (PCOR) that intentionally involves consumers throughout the research process. The network’s approach to achieving its goal is to enroll a large number of activated members of the hereditary cancer community, maintain a governance structure that includes patients and advocates to oversee all aspects of the work, and compile and account for people’s real-world experiences in ways that help to shape future priority research activities.

At a baseline level, patients and other relevant stakeholders are engaged in ABOUT via inclusion in a contact database composed of patients, family members, people with gene mutations, healthcare providers, educators, and other stakeholders which reaches more than 27,000 contacts. The contact registry does not collect data, but is a directory of individuals who have opted to receive information on a monthly basis on programs and research studies in which they can engage or might be interested. ABOUT prepares volunteers to engage in research advocacy through their FORCE Research Advocate Training (FRAT) Program. Currently there are 89 trained advocates and 31 in training. Finally, the network also maintains a dedicated governance body composed of patients, advocates, researchers, and clinicians. Since its inception, the 15-member, patient-majority Steering Committee ensures the patient voice is central to oversight of network activities and ensuring the network remains accountable to its mission.

ABOUT returns value to participants by focusing on strategies—co-developed with patients—to elevate their voice in hereditary cancer research and accelerate the completion of research through promotion. For example, the network has developed trainings to help patients harness their personal experiences when providing input into the research process. Connecting patients to relevant research has also been an important focus, and the network has done extensive work developing tools to educate patients in plain language about ongoing clinical studies that may be enrolling as well as to disseminate research findings with contextual information about the research’s relevance to clinical care. Finally, it is important to note that researchers are also important constituents of ABOUT. The network aims to develop tools that will return value to both patients and researchers in order to help maximize the value and relevance of hereditary cancer research for the patient and healthcare end-users. The tool featured in this case study, ABOUT’s Research Collaboration Page, is an example of a strategy for returning value to both patients and researchers. Because this tool is still in development, the case study focuses on its design rather than its implementation.

About the Tool. The ABOUT website (aboutnetwork.org) includes a section dedicated to research that facilitates involvement in research specific to ABOUT patients and stakeholders. This section houses a research prioritization tool, descriptions of ongoing research projects, summaries of research findings and opportunities to enroll in research studies. This section will also serve as the home for their newly developed Research Collaboration Page. A mock-up of the page is provided in Figure 5. The purpose of this page is to effectively communicate information to the ABOUT community about ongoing research projects relevant to hereditary cancer. It is intended to answer the following questions:

- Who is doing research now?
- What type of research is being done?
- How far along is the research?
- How is ABOUT helping to facilitate the research?
- How can the ABOUT community help?
Study Content

The main page will include study titles, brief teasers and a graphic illustrating the stage of the research (described below). Users may choose to click on a study title or a "read more" button to go to that study’s detail page and learn more about the project. Whenever researchers want to work with ABOUT, they must complete a research collaboration form. This form requests:

- General information about the study (research question, goals, study design, etc.);
- How the researcher wants to collaborate with ABOUT
- A description of how the research is patient-centered;
- Whether the researcher would like feedback on the study from the ABOUT community.

This information will be presented on the detail page and communicated in plain language, so the patient community can learn about ongoing research studies and how the research is designed to address topics of priority and interest to them. They can also learn more about the role ABOUT is playing in helping to facilitate the project and if there are opportunities for the broader community to contribute, either as a partner or a participant.

Research Staging

An important aspect of describing the research studies will be the categorization by research lifecycle stage. This allows for each study to be categorized as being in one of four phases: Plan and Prepare, Conduct Research, Evaluate, and Share and Use. These align with phases where ABOUT plays crucial but distinct roles in helping facilitate research projects. Phases along with their descriptions are presented in Table 6 below.

Table 6. ABOUT Research Collaboration Page: Research Stage Phases & Descriptions

<table>
<thead>
<tr>
<th>Plan &amp; Prepare</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Generating and prioritizing research questions based on gaps in science and patients’ needs</td>
</tr>
<tr>
<td>- Patients/advocates are reviewing and providing input on study design</td>
</tr>
<tr>
<td>- Writing a study proposal</td>
</tr>
<tr>
<td>- Applying for funding</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Conduct Research</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Enrolling patients</td>
</tr>
<tr>
<td>- Patients/advocates are assisting the study team</td>
</tr>
<tr>
<td>- Collecting data</td>
</tr>
<tr>
<td>- Monitoring study progress</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Evaluate</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Analyzing data</td>
</tr>
<tr>
<td>- Drawing conclusions</td>
</tr>
<tr>
<td>- Suggesting next steps or areas of future research</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Share &amp; Use</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Publishing in a peer-reviewed journal</td>
</tr>
<tr>
<td>- Sharing results with the patient community</td>
</tr>
<tr>
<td>- Incorporating findings into programs and practices</td>
</tr>
</tbody>
</table>

The ABOUT Network has found that many patients are often unaware of research activities unless they are late stage clinical trials or completed studies with results available. By presenting all ongoing research, this new page will help educate the ABOUT community about the volume of ongoing studies and the nature of research—that it is a process with multiple stages of activity. Breaking each study down and showing its current stage also presents an opportunity to inform the community how ABOUT is taking an active role in facilitating the work and helping to make it more patient-centered.
### Search and Sort Features

To enhance user experience, research study descriptions will also be tagged according to category (e.g. cancer risk, early detection, etc.), relevance (e.g. cancer survivors, previvors/high-risk people, men, women, etc.), research stage, or pre-defined keywords. Users will also have access to a search bar to enter free text and search by terms of their own choosing.

### Comment Functions

In addition to the page serving as a tool for communicating research activities to the patient community, the page will also provide a feedback loop back to researchers. Study detail pages will include functionality for the patient community to submit comments to researchers to provide feedback on the study or ask questions. This feature will help remove barriers that traditionally exist between patients and researchers by facilitating direct communication and collaboration. Notably, this offers researchers an avenue for obtaining input that could help make their studies more patient-centered.

### Development Experience

The notion for the Research Collaboration Page was borne out of the expressed interest among the ABOUT patient community to know what research is happening and in what ways ABOUT and the broader ABOUT community are involved. The ABOUT team leveraged existing tools, such as their research prioritization rubrics and landing pages, as starting points to design the new page. Key steps included:

- Working iteratively with the ABOUT Steering Committee to ensure patient and other stakeholder perspectives were incorporated into the page’s purpose, design and usability;
- Leveraging existing pages and tools to maximize efficiency and match the look and feel of resources with which the ABOUT community is already familiar;
- Rolling development of the new page into their broader plan for website and logo redesign to minimize workflow disruptions and consolidate website updates.

The network has found that working with the Steering Committee has been instrumental in ensuring that the Research Collaboration Page will be accessible and useful for research participants. Steering Committee input has been critical for refining the research lifecycle phases and definitions, organizing layout and communication approaches, and outlining functionality requirements.

Concurrent with design of this new page, the ABOUT team has been pursuing a broader website redesign that also involved significant Steering Committee engagement. This required the

<table>
<thead>
<tr>
<th>Table 7. ABOUT Research Collaboration Page</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Project Aim(s)</strong></td>
</tr>
<tr>
<td>- Improve informed decision-making and health outcomes for people affected by hereditary breast, ovarian, and related cancers by facilitating patient-centered outcomes research (PCOR) and engaging consumers throughout the process</td>
</tr>
<tr>
<td><strong>Goal(s) of Tool</strong></td>
</tr>
<tr>
<td>- Inform network members of ongoing hereditary cancer research studies</td>
</tr>
<tr>
<td>- Communicate the reason behind the research, relevance of the research, where the project is in the research lifecycle</td>
</tr>
<tr>
<td>- Communicate how ABOUT is assisting the research process</td>
</tr>
<tr>
<td>- Communicate where there are opportunities for the broader community to participate</td>
</tr>
<tr>
<td><strong>Key Features &amp; Functions</strong></td>
</tr>
<tr>
<td>- Full chronicling of ongoing studies in collaboration with ABOUT</td>
</tr>
<tr>
<td>- Easy-to-read presentation of study information</td>
</tr>
<tr>
<td>- Describes how research is patient-centered and how ABOUT is involved</td>
</tr>
<tr>
<td>- Features to support navigating study listing by pre-defined tags, including tags focused on relevance to user characteristics</td>
</tr>
<tr>
<td>- Infographics which signify study phase</td>
</tr>
<tr>
<td>- Free-text research study search capability</td>
</tr>
<tr>
<td>- Comment function to allow users to engage with researchers</td>
</tr>
<tr>
<td><strong>Returning Value Approach</strong></td>
</tr>
<tr>
<td>- Provides a feedback loop to the ABOUT patient community regarding ongoing research relevant to their needs and priorities</td>
</tr>
<tr>
<td>- Empowers patients and other stakeholders to provide feedback directly to researchers regarding their studies</td>
</tr>
<tr>
<td>- Brings value to ABOUT by heightening visibility of its role in facilitating patient-centered research related to hereditary cancer</td>
</tr>
<tr>
<td>- Brings value to researchers by heightening visibility of their ongoing work and providing an avenue for receiving direct patient input on their studies</td>
</tr>
</tbody>
</table>
development of multiple parallel work streams to coordinate design and testing, which generated some logistical challenges. Navigating these challenges, particularly in terms of work stream sequencing, was important and ultimately ensured a coordinated rollout where the new page is well-integrated in the broader website revision.

Rollout is planned for Fall 2020, and ABOUT is developing a strategy to monitor implementation. One challenge the team anticipates is that it will be difficult to solicit relevant feedback on certain types of research activities. In efforts to promote the tool widely, it is possible that ABOUT could invite widespread input and thereby run the risk of receiving a large number of potentially irrelevant comments. In order to mitigate this potential burden, the team aims to identify ways for culling large amounts of information in order to ensure the capture information that is both comprehensive and applicable.

The team is also focused on tracking success. The network has learned that a major challenge in research is that results are seldom disseminated broadly, and participants rarely receive the results of research they previously participated in. ABOUT hopes the Research Collaboration Page will address this gap by making information about research studies more widely available. However, success will rely on the network’s ability to promote the page and how users engage with content. Once launched, the network plans to track metrics demonstrating use of the tool. These might include the average time viewers spend on a page, the number of page views, or the number of distinct engagement activities (e.g., comments) made regarding research studies.

Beyond tracking page traffic metrics, the network intends to explore more nuanced ways of assessing success. For example, soliciting participant feedback to gauge satisfaction. However, participants tend to be more appreciative of research efforts when they result in the generation of relevant findings or the creation of helpful interventions. The purpose of this page is to show the full landscape of research, not just completed research or studies with the most impactful results. It is unclear if this difference in scope will influence the level of satisfaction of users. As a result, the network will consider additional measures of success, such as the solicitation of impact statements from the organizations involved in the research (e.g., “we’ve helped to enroll X people for X number of studies). The network anticipates making improvements in the page as feedback is received from the community about its relevance, value and usability.

Lessons Learned. While digital engagement is becoming increasingly popular among PDRCs, ABOUT’s applications of digital tools and technologies are innovative relative to the field of hereditary cancer research. The network’s hope is to attract more investigators to hereditary cancer research by showing them that there is a growing landscape of research activities, already thriving, to which they (and other stakeholders) can contribute. Once ABOUT can estimate the tool’s success in engaging target audiences, it will know how much to invest in different aspects of its digital engagement strategy.

ABOUT has always been a remote, digitally-based organization; the network asserts that digital tools can transform the return of value by helping users better understand their potential roles in research and to comprehend the ways their input can have a tangible influence on the research process. Digital tools can be used to facilitate awareness-raising among research partners. They can also be a resource-efficient means of broadly disseminating information about research activities and subsequent results ABOUT has faced challenges associated with maintaining engagement of a representative community of stakeholders using its digital tools. However, the network aims to address this by partnering with other organizations and by dedicating resources in ways that specifically support the engagement of traditionally underrepresented populations.
Digital Strategies for Returning Value to Research Participants

COPD Foundation PPRN: Bridge Project’s Use of COPDF360 Social

**Case Study Authors:** Cara B. Pasquale, MPH\(^a\); Gretchen M. Mccreary, MA\(^a\); Vincent M. Malanga, BS, MCP\(^b\); Barbara P. Yawn, MD, MSc\(^c\)

**PDRC LN Contributors:** Elizabeth Cope, PhD, MPH\(^b\); Rachel Dungan, MSSP\(^b\); Priya Govil\(^b\)

**Affiliations:**
- a. COPD Foundation, Miami, FL, USA.
- b. AcademyHealth, Washington, DC, USA.

**About the Network.** The COPD Foundation serves as the home for the COPD Patient-Powered Research Network (COPD PPRN)—a patient registry of currently more than 8,000 individuals with COPD or who at risk of COPD and who have agreed to share their health information and participate in research.\(^i\) Overseen by a patient-led governing board, this registry allows people with COPD to share their experiences through surveys developed by their peers, access educational information, and learn about studies for which they might be eligible to participate.

The COPD Foundation is guided by its aim to “prevent and cure Chronic Obstructive Pulmonary Disease and to improve the lives of all people affected by COPD.” The Foundation’s multifaceted work spans research, advocacy, and awareness-raising activities, and involves approximately 50,000 affected stakeholders (approximately half of whom identify as COPD patients).

The Foundation’s overarching engagement strategy acknowledges the diverse needs of individual stakeholders and provides correspondingly varied channels for soliciting people’s input or involvement through its web-based platforms. Using different digital platforms designed to support multiple modes of engagement, the Foundation meets people where they are by lowering common barriers and recognizing individual variation in motivations for and goals of engagement. Accordingly, the platforms fall along a continuum from social engagement to research engagement (**Figure 6**) with both available as digital tools for appropriate projects. In acknowledgement of these two distinct engagement goals, the Foundation intentionally did not incorporate a single sign-on setup. The COPD360social platform is designed to support social networking and community cultivation for a broad audience of people affected by COPD. The COPD Patient-Powered Research Network (PPRN) platform, specifically not nested within the social platform, targets those interested in the broad spectrum of COPD related research participation or engagement. To facilitate movement of interested COPD360social participants from involvement only in the social network to participation also in the COPD PPRN community. Essentially, stakeholders are invited to contribute to each community in ways that are comfortable for them, while also having exposure to new opportunities and the mobility to choose and explore the engagement platform they deem best for them at that time.

**Figure 6. COPD Foundation communities and the continuum of digital tools that support them.**

For those interested in research participation, the COPD PPRN shares information through multiple digital tools including community-specific newsletters and webinars. COPD PPRN members also have personalized dashboards (**Figure 7**), where they can review their personal research results or receive tailored surveys. This targeted approach ensures that participants receive only those opportunities for which they are eligible, minimizing their fatigue from having to sort through irrelevant calls for participation, and directs them to studies that might prove most relevant or personally beneficial. Via that dashboard, researchers can also provide individual and aggregate results to patient participants. Stakeholder and PPRN member feedback has indicated that participants especially appreciate comparison reports, demonstrating how their individual results compare with those of others who share similar traits or characteristics in addition to results of studies in which they participated. These dashboards constitute one of the Foundation’s most important vehicles for returning value to participants. The collection of this much information from participants is partly what helps to sustain and power the Foundation’s research and programmatic work; in return for participants’ commitment of time, effort, and data – the Foundation feels strongly about ensuring that participants receive results in ways that ultimately benefit or improve their own experience with COPD. Creating feedback loops like this helps the Foundation to not only give network members the information they need to stay actively engaged; it also helps to reinforce both trust and communication between stakeholders and the broader research enterprise.

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\(^i\) [https://www.copdfoundation.org/Research/Registries/COPD-PPRN-For-Researchers.aspx](https://www.copdfoundation.org/Research/Registries/COPD-PPRN-For-Researchers.aspx)
About the Tool. As shown above in Figure 6, there are channels for feeding the work of the COPD PPRN into broader engagement activities for the COPD360social community. One such mechanism for connecting the two groups is the “Bridge Project” for which an initial focus was creation of a patient-driven COPD research agenda. Responding to shifts in needs and priorities in response to the global pandemic, the team added an additional focus to develop a separate patient-driven research agenda highlighting the mental health and wellbeing consequences of COVID-19 for COPD patients. The development of these research agendas began with surveys collected in the COPD PPRN. The COPDF then used the COPD360Social platform as a digital tool to expand engagement of the COPD community and better target the proposed research agendas ensuring the end result reflected the broadest array of perspectives. Recognizing the significant gaps between COPD research being funded, and the priorities or perspectives of key stakeholders, the Foundation viewed this exercise as one way to help amplify patient and caregiver voices in discussions about future COPD research. Ultimately, the aim was for emergent research on this topic to align with patients' and caregivers' goals, needs, and preferences such that it would better inform patient-centric COPD care and interventions. Core elements of the Bridge Project and use of the COPD360 Social platform as a digital research tool are described below and in Table 8.

Ideation Process
To populate the list of potential research ideas, the Foundation solicited ideas from the PPRN community. This involved requesting input from approximately 7,800 PPRN members via a digitized survey on potential research topics and ideas of interest. Qualitative analysis of the survey responses initially produced 550 distinct ideas, which were then narrowed to 500 distinct ideas following a de-duplication process. These ideas (and six initial categories for organizing them) were then vetted by the PPRN community and the PPRN Governing Board. Following that initial refinement, a culled list of 25 ideas was published on the COPD360social site for review by members of the broader community.

Using Digital Tool for Voting Function
Patient and caregiver members of the COPD360social site were invited to vote and comment on the 25 ideas generated by the PPRN in a public forum. Over the course of three weeks, COPD360social members were allowed to cast up to 30 votes on the presented ideas. Individuals were at liberty to assign multiple votes (up to five) to a single topic to signify particular priority. Throughout the voting period, they could alter or reassign their votes as desired.

Comment Function
The COPD360social ideation tool includes the functionality to allow members to add comments as well as vote on the research items. These comments provided the Foundation with deeper insights into the members rationale.

User Support for 360Social as a Digital Tool
It was recognized that, as is the case with most digital tools, COPD360social's usefulness could be limited by users' knowledge and comfort navigating the resource. Accordingly, the team produced brief “whiteboard” videos (lasting about approximately two minutes each) that described and depicted specific actions to help users access and engage with the tool. These videos are similar in nature to the series of whiteboard videos available through their COPD360social platform to assist users in accessing that suite of tools (Figure 8).

Implementation Experience. Prior to launching the prioritization process with the full community, the Foundation conducted a pilot to refine the process and technology. They engaged patients in developing and recording a series of patient stories. These stories were then listened to by a small group of key stakeholders and used to generate the list of topics. This list of topics was then shared with a small subset of patients for them to prioritize and cast votes.

During the full launch, which invited topic ideation from the broader COPD PPRN membership, the Foundation encountered an unexpected challenge. As part of their initial data analysis, they found they needed to solicit targeted stakeholder input on the controversial nature of some of the questions that had been proposed, and whether they were appropriate for the network to entertain,
with or without refinement. The COPD PPRN Governing Board then played a role in reviewing the topic listings and deciding how best to use the COPD360social platform to best communicate with network members about these topics.

Overall rollout of the voting feature was smooth, given the earlier piloting. The Foundation also reinforced earlier learnings about the importance of providing the guidance and training needed to minimize barriers to engagement through the incorporation of whiteboard videos and other help features. This extra step helps people overcome barriers to engagement and enables the involvement of people who may otherwise be underrepresented in the activities of the Foundation.

Through this tool and associated process, the Foundation sought to return value by honoring people's personal agency, and inviting their involvement in the research agenda-setting process—and by creating opportunity for cultivating empathy through community and connectivity, between network and research team members. The ultimate return of value, however, would take the form of eventual uptake of proposed priority topics by the research community. Seeing these topics or questions emerge in calls for proposals or others’ research work will demonstrate the resonance of this activity for the field, and will help to ensure that research gets conducted on topics of relevancy for the COPD-affected community.

Success of the prioritization process was assessed in multiple ways. The initial list of topics was developed from the responses of 550 PPRN members, and the final set of topics was voted on by 214 COPD360social members. Such strong engagement from their communities indicates the resonance of the topics and the value provided through participation in the process. In addition, the Foundation received positive anecdotal feedback that participants appreciated the opportunity to contribute to this process and encouraged them to host similar activities in future. The Foundation continues to consider options for conducting more robust evaluations of success. Feedback from participants provides one level of input, but a more systematic evaluation of whether these tools and efforts “are working” is needed. Assessment of topic uptake by researchers and downstream effects on patient outcomes would better characterize impact, but comes with an array of challenges ranging from the time, resource, and bandwidth to carry out the evaluation.

### Table 8. COPD Foundation Bridge Project & use of COPD360social as a digital tool

| Goals of the COPD PPRN | - The COPD PPRN is a research registry housed at the COPD Foundation and overseen by a patient-led governing board  
- The registry aims to collect and share data to research that can ultimately lead to a deeper understanding of COPD and related conditions, and to treatment options that may improve quality of care or health outcomes for COPD patients |
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Goals of the BRIDGE Project</td>
<td>- Create a patient-driven research agendas focused on a) COPD in general and b) on the mental health and wellbeing consequences of COVID-19 for people living with COPD</td>
</tr>
<tr>
<td>Goal(s) of the Tool</td>
<td>- Integrate members of the Foundation’s broader COPD360social community in the research agenda development process initiated within the COPD PPRN</td>
</tr>
</tbody>
</table>
| Key Steps | - Digital survey to COPD PPRN membership to solicit research topic ideas for:  
  - A general COPD research agenda  
  - A research agenda to address mental health and wellbeing consequences of COVID-19.  
  - Qualitative analysis conducted by the research team to de-duplicate and organize research ideas into refined list  
  - Review by the COPD PPRN Governing Board to finalize the list of ideas for prioritization  
  - Use of the COPD360social platform to rank research priorities by the larger COPD community  
  - Survey that allowed voting on the COPD360 Social website (30 votes per person; maximum 5 votes per topic) to rank items generated from PPRN surveys. |
| Key Features of 360Social as a digital tool | - Functionality of COPD360social website to promote deeper patient engagement with the content  
  - Tutorial “whiteboard” videos to help users navigate site tasks and features  
  - Dissemination tools (static content in portal, blogs, webinars) to provide a feedback loop for patients to learn the results of the prioritization activity |
| Returning Value Approach | - Engaging full COPD community available to COPDF  
- Pursuing research studies of highest priority to patients  
- Empowering patients to drive the research agenda  
- Providing patients with a sense of agency in the research process  
- Framing value from both a patient satisfaction perspective as well as an outcomes perspective |
to the competing influences and time lags that would complicate interpretation. Nevertheless, the Foundation considers improving the lives of those affected by COPD as its north star, and continues to explore ways to hold itself accountable to this goal.

**Figure 8. Whiteboard Videos.**

Dissemination Process
Following the team’s analysis, outputs from the activity were shared with participants in the COPD360social and COPD PPRN platforms in the form of blogs, webinars, and newsletters. Results were also delivered to the COPD Foundation’s Medical & Scientific Advisory Committee to help facilitate direct translation of prioritized ideas into the Foundation’s future strategic planning and project activities.

**Lessons Learned.** The development and implementation of the tools used to implement COPDF’s Bridge Project development of patient driven research agendas, allowed the Foundation to integrate two distinct but overlapping communities of constituents and to tap into their insights to ensure the final product reflected the widest array of perspectives possible. This involved thinking critically about the roles and responsibilities of both types of community members and, accordingly, about the platforms that might serve as the best vehicles for facilitating engagement within or among them. This project was based in the COPD PPRN but utilized the opportunities and functionality of the COPD360Social platform as a digital to enhance the generalizability and value of the final product and outcomes. Moving forward, the team will consider how best to invest in new technology and digital tools as needed to connect and coordinate different engagement efforts, with the goal of continuing conversations throughout the “life course” of a project, or a participant’s engagement with the Foundation. While some of these investments may be crucial for improving the return of value to engaged stakeholders, there will be additional considerations related to development time, cost, and effort.

The Foundation considers digital tools to be a vital component of their engagement strategy, as they offer value that is unique and distinct from the value returned through non-digital strategies. They scale easily and enable diverse and geographically dispersed community members to access the Foundation’s resources. This is particularly important for the COPD community, where the ability to travel is often limited by symptom or logistical constraints related to the condition (e.g. traveling with oxygen). The benefits of human connection obtained through in-person engagement should not be underestimated, however, the Foundation has seen digital tools create links to these endeavors, as was the case when a group of network members used the social network to coordinate the logistics for an in-person meeting. In this instance, the digital tool was used to support physical human interaction. As the global community becomes more reliant on virtual connecting and convening platforms (e.g. in response to the pressures of COVID-19), digital tools will only grow in significance, as they help people come together during times that necessitate physical separation. This brings inequities in access to digital technologies into greater relief. If these trends become the norm, and virtual spaces become our most common connecting spaces, it will be necessary to identify strategies for better engaging individuals with limited access or who are not digitally savvy.
Digital Strategies for Returning Value to Research Participants

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Acknowledgments: In addition to the case study authors, IBD Partners would like to recognize current and former team members who have made the IBD Partners portal a success: Investigators Dr. Robert Sandler, Dr. Millie Long, and Dr. Edward Barnes; current Patient Governance Committee members David Walter, Jennifer Dorand, Guy Havelick, Robbie Maris, and Natalie Holman; and Angela Dobes, Wenli Chen, Xian Zhang, Lauren Matthews, Kyra Catabay, Amber Robb, Beth Jaeger, Brittany Becker, Jessica Burris, Sue Johnson, Brian Price, Sean Ahrens, and Andy Garb.

About the Network. IBD Partners is an online research network focused on inflammatory bowel diseases (IBD) and led by a partnership between the Crohn’s & Colitis Foundation (the Foundation) and the University of North Carolina (UNC) School of Medicine. Launched in 2014, the network’s mission is “to empower IBD patients, researchers, and healthcare providers to partner in finding answers to research questions patients care about and ultimately improve the health and lives of patients living with these conditions.” The network was borne out of the need for research to bring patient priorities and the patient experience front and center. Despite the breadth of knowledge patients have from their lived experiences with these diseases, their perspectives are often overlooked in favor of more clinical, traditional research approaches in which patients play the role of giver of data and samples. IBD Partners turns this traditional research paradigm on its head by encouraging patients to work alongside researchers as partners in the investigative process.

Patient engagement occurs in two primary planes. First, the network’s research and project management team, responsible for tactical implementation of network strategies, receives guidance from the Patient Governance Committee (PGC). This six-member committee of IBD patients meets monthly and is responsible for setting policies, overseeing the research agenda, contributing to protocol development, and ensuring network activities are fully aligned with the mission. This high-intensity, but narrow reach, engagement is complemented by approaches that leverage the broader network. At a current membership of approximately 16,000 patients, the network uses a suite of digital tools to foster engagement in the research process by enabling members to: prioritize a patient-centered research agenda, join research studies as participants, contribute patient-generated health data (PGHD), explore the PGHD to learn more about the disease, and collaborate with researchers in the conduct and dissemination of patient-centered research.

Traditionally, research has relied on the personal notion of altruism as the driving motivation for patient participation in research. However, altruism should not be seen as a sufficient or sustainable method of delivering value to participants. IBD Partners aims to provide value to its members through the following avenues:

- The conduct of high-impact research that directly addresses topics of priority to IBD patients;
- Empowerment of patients to partner as collaborators in the scientific process;
- Building capacity for connections and understanding through direct collaboration between patients and researchers;
- Emphasizing transparency in the research process by sharing with patients how data they contribute is used for research;
- Building trust in the scientific enterprise through involvement and continuous communication feedback loops through each phase of the process.

The sections below focus in particular on the network’s delivery of value through its digital tool for collaborative research topic ideation and prioritization.

About the Tool. The IBD Partners’ web-based participant portal incorporates a range of functionality including engaging members in research prioritization, supporting contribution of PGHD and mobile health data, enabling viewing of PGHD to support disease management, and facilitating dissemination of information. Specifically, the research prioritization platform (Figure 9) invites the broader IBD Partners patient community to drive the network’s overall research agenda. This interactive, collaborative platform allows patients to pro-
pose, discuss, and vote on specific research questions, as well as track their uptake by the network. The result is a crowdsourced research agenda that is continuously updated in real-time. Specific features are described further below and in Table 9.

Proposing and Discussing Topics
Notably, the platform intentionally does not include the common feature of general chat or message board; this helps to restrict its use for conversations directly related to the research activities. If individuals want to contribute by posing or commenting on questions, they must log into the platform. This acts as a mechanism for self-moderating, and it invites a kind of “opt-in” participation that helps to focus the conversation. Notably, the community has not suffered from distracting or harassing user comments requiring significant moderator involvement.

Researchers can also interact with users of the platform by adding comments (always identified as “researcher” comments). This functionality invites researchers to contribute to the greater dialogue in meaningful, but targeted, ways. For patients who may be newer to research activities, processes, or terminology, such a platform also helps to demystify engagement in research by creating closer and more transparent communication links between participants, researchers, and other site administrators or network staff members.

Voting
An important feature of the platform is the ability for participants to vote on research topics they consider important or high priority. Each member is limited to five total votes that can be distributed as desired. If a new research question gets added and participant has already used all five votes, they must “unvote” for one question in order to indicate support for the new one. Limiting the number of votes per participant helps patients prioritize questions that are most important to them. Limiting the number of votes also helps to ensure that the majority of votes are not being cast by a select few, and that the voting outputs reflect the perspectives of diverse members—who vary by diagnosis, stage of patient journey, age, race/ethnicity, gender identity, and geography. Ultimately, the goal was to ensure representativeness of the population engaged in voting such that the eventual prioritized agenda could be reconciled with what is most important to the broad IBD community.

Tagging Features
The research questions can be tagged according to multiple parameters to help draw attention and invite further review. Tags include: Newest, Most Voted, Most Discussed, and “Hottest” - which is a composite of the aforementioned criteria. Buttons are located at the top of the page to allow users to quickly reorganize the listing of proposed ideas according to the tag of interest.

Researchers can also apply tags, signified by the overarching “Reviewed by Researchers” tag. These tags are designed to signal importance or calls to action. For example, research team members might apply the “Top Priority” tag to reflect urgency, or the “Great Fit for Partners” to reflect alignment between the proposed idea and the reach or resources of IBD Partners. Further, an idea might be tagged as “Study Underway” to reflect uptake of the research question and incorporation into an ongoing IBD Partners study.

Feedback Loops
The IBD Partners participant portal also includes a number of features that help to create feedback loops that integrate the user experience with the broader work of the network. For example, once a question changes status (i.e., if a proposed question prompted creation of a new study) patients can be contacted by the research team indicating that they can enroll in the study and/or apply to serve as more engaged patient research partners and assist with study design and conduct, if interested. The platform also provides links to current studies that are relevant to the posed questions—including some studies conducted by external entities—as well as results from published studies. These features allow participants to track the research process, from topic generation to results publication, and see themselves in that process.

Implementation Experience. The online portal was developed via an iterative process with substantial involvement from the PGC. Early deployment had limited functionality and usability features. Through a process of version rollout and review of user feedback, the IBD Partners team was able to refine the tool and improve user experience. For example, proposed questions were initially organized into content or topic categories (e.g., diet, patient-reported outcome, medication toxicity). However, user feedback indicated that some of the categories were either too narrow or too similar to other questions. Through rounds of testing and solicitation of pa-
tient and researcher input, the categories were subsequently revised. Later adjustments to the platform included the addition of free-text search and text recognition functionalities to avoid duplicate questions. For example, if someone were to ask, “How does dairy affect IBD?” the text recognition functionality would be able to discern whether or not similar questions have already been asked. The system might flag related questions such as “Can I drink milk with IBD?” and prompt a pop-up window notifying the former poster about this similarity. These features were important additions for streamlining the creation and curation of the research agenda, and there is recognition that the implementation process might have been smoother had more user preference/requirements data been gathered prior to initial rollout.

Markers of success include breadth of platform use as well as topic uptake for study development. As of June 30, 2020, the prioritization tool has been used by 988 participants, resulting in 262 research ideas, 345 comments, and more than 2,830 votes. In addition, researchers have actively pursued several studies based directly on the questions posed in the platform. For example, a recently funded study examining dietary treatments of IBD was in direct response to the top research priority from the platform. To further enhance the network’s understanding of this tool’s value, IBD Partners tracks metrics related to how many investigators have used and shared data from the platform. While this does not involve mapping specific research questions to specific publications, it has involved tracking the total number of publications coming out of the cohort (approximately 40 to date).

Despite successes observed to date, the network sees opportunities to continue improving and evaluating the platform. In particular, there is interest in increasing attention related to marketing and promoting the tool. Contributions from nearly 1,000 participants is an important success, but it still represents only 6.5% of the network’s membership. There is interest in broadening and diversifying the engagement to ensure the agenda reflects the priorities of the full membership. At the same time, there is a desire to continually evaluate if this approach is optimized for the goal. While the platform includes a number of automated features, it still requires regular manual review, maintenance, and curation. In a resource-limited context, it is important to reflect on whether the value of the output is appropriately matched with the level of effort and resources required to produce it.

**Lessons Learned.** Digital tools offer valuable approaches to engaging participants on a large scale in a resource efficient manner. As an online research network, digital tools allow IBD Partners to meaningfully involve a large and diverse group of IBD patients in the research process—soliciting an array of perspectives that shape the network’s leadership, governance, priorities, and activities. At the same time, there are challenges associated with securing and sustaining engagement from a truly representative patient population. There is a digital divide in this nation, and not everyone has equal access and/or literacy. Thus, it is always important to consider digital engagement approaches in tandem with non-digital strategies to ensure the work of the network is a true representation of the priorities, needs, and interests of the patient population at-large.
ImproveCareNow: Pipeline to Engagement

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Acknowledgments: The work presented in this case study was led by the ImproveCareNow Engagement Team consisting of Sydney Bogardus, Mary Havens, and Chris Keck with Principal Investigator Michael Seid, PhD and Co-Investigator David Hartley, PhD.

About the Network. ImproveCareNow (ICN) is a 501(c)3 non-profit organization with its central office at the University of Vermont and which works closely with its strategic partner, the Anderson Center for Health Systems Excellence at Cincinnati Children's Hospital Medical Center. Its mission is to "transform the health, care and costs for all children and adolescents with Crohn's disease and ulcerative colitis (Inflammatory Bowel Disease or IBD) by building a sustainable collaborative chronic care network.\(^{25}\)” Together with its more than 100 partnering health care centers, ICN engages patients, families, clinicians, and researchers in a learning health care system to accelerate discovery, improve care quality, and better the lives of those affected by IBD. This creates opportunities for patients and clinicians to collaborate in co-producing the information, knowledge, and know-how to improve health and health care for IBD patients.

ICN emphasizes the importance of embedding channels for patient and stakeholder contribution at all levels of network activity. They are represented in important community governance structures, including on both the Board of Directors (BOD) and the Community Council: a blended group of network stakeholders tasked with providing guidance, setting priorities, and reviewing materials for the BOD and other executive leadership figures. The network's Research Committee also includes several patient and patient parent members, and every research proposal is reviewed by at least one IBD patient or caregiver. In addition to promoting patient and caregiver involvement in leadership and research decision-making, ICN also has groups dedicated to these stakeholder perspectives, including a Patient Advisory Council (PAC) and Parent Working Group (PWG), both of which set their own objectives and independently develop tools and resources for the network and its membership. For example, toolkits created by the PAC focus on topics of particular relevance to IBD patients, such as special considerations for traveling, attending college, and navigating body image issues. Once finished, the network hosts PAC materials on its website, making them publicly available. The philosophy is that the patients and parents are experts in their disease experience, and they know the resources that are needed to support others. In this realm, the network sees its role as providing them with the forum to work together and the platform to share their products broadly.

Aiming for complete transparency between stakeholders in its collaborative processes, ICN employs an “all teach, all learn” collaborative approach to medicine and strives to return value to network members by providing them with as much information as is needed to encourage their engagement with the network – and in their clinical encounters. This intentional provision of information, paired with open requests for feedback from network members, creates a cycle of sharing that empowers and engages network members. Ultimately, this removes barriers to communication and collaboration that might otherwise inhibit network members from communicating back about their preferred ways and means of deriving value from involvement. This feedback loop reinforces strong relationships between all involved parties, allowing the network to achieve greater and more targeted impact while supporting the IBD community.

About the Strategy. ICN uses a range of digital tools to support collaboration among its various governance and working groups. While some of this activity occurs behind secure login to manage access to works in progress, virtually all of the network’s resources, tools, and research outputs are publicly available on the website, in line with their commitment to transparency as a core value. The strategy featured in the present case study is the network’s pipeline to engagement, which channels IBD patients from awareness to active involvement through a series of digital tools: tablet sign-up, e-newsletter, and website. Specific features are outlined below and in Table 10.

Tablet Intervention: Generating Awareness

Initially, ICN focused its recruitment efforts on getting doctors and care centers to join the network. Outreach to patients was often accomplished through the distribution of flyers at participating clinics. This approach leverages the trusted relationship between patients and providers, increasing the likelihood of consent. Even when explicitly shared with patients by their doctors, however, this approach required patients to remember to bring the flyer home and navigate to the appropriate website to complete registration. Accordingly, ICN sought to close this gap by working with providers to share network information and invite consent through the use of digital tablets.

\(^{25}\) https://www.improvecarenow.org/purpose-success
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In 2018 ICN partnered with the first of two of their care centers as pilot sites for testing the new intervention. An important aspect of the intervention was ICN’s provision of the tablets to the centers. Tablets were intended to be integrated into each center’s workflow as appropriate, and thus could include additional content to facilitate care delivery or patient-provider interaction, as needed by the respective center. In addition to the items added by the centers, each tablet came with instructions on how to find ICN information and access the CIRCLE sign-up page as well as a script for introducing ICN and the tablet to patients and families. During clinical encounters, providers would inquire about patients’ interest in learning more about the network. Interested patients would then review introduction materials on the tablet, learning about the network, its mission, and its work conducting research and improving care. Patients interested in learning more would be prompted to provide their email address, which would automatically sign them up to receive the CIRCLE Newsletter. This process introduces patients to the potential value they could receive through their participation in an established and trusted patient community, which could support them as they initiate or continue to navigate their own patient journey with IBD.

**CIRCLE Newsletter: Bridging to Community**

The second step in the series of digital resources is CIRCLE: the network’s email-based newsletter to members and other key stakeholders, which offers an introduction to the network, along with other informational content. CIRCLE is a bi-weekly e-newsletter delivered via email with content curated based on feedback from patient informants, who expressed having wanted or needed certain types of information following their IBD diagnosis. Each newsletter features a range of content, including blog posts written by IBD patients, stories of how patients are working together with clinicians and researchers, opportunities to engage in network activities or preview new tools/resources, and the latest research updates (Figure 10). The aim is to draw new registrants’ attention to network activities and outputs by providing trusted, relevant, and relatable content. Often, the newsletter contains teasers that invite recipients to click through to the network’s website to access the full content. Once on the website, patients can access the full range of research, educational, and supportive content, and consider opportunities for involvement with the network.

**ImproveCareNow Website: Connecting to Opportunities and Resources**

From the CIRCLE Newsletter, recipients can access full content on the ICN website (ImproveCareNow.org), where the intent is for them to navigate the broader site in a self-directed manner. Once on the website, patients have the ability to explore a number of pages and resources with content targeting their perspective. This includes access to material such as:

ICN Research Explained: Lay summaries of ICN research findings developed by the Research Committee in partnership with the PWG to ensure the full ICN community can take advantage of what has been learned (see Figure 11 for an example).

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**Table 10. ImproveCareNow Pipeline to engagement**

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- Transform the health of all children and adolescents with Crohn’s disease and IBD by building a sustainable collaborative and chronic care network which enables patients, families, clinicians and researchers to work together - accelerating innovation, discovery and the application of new knowledge.</th>
</tr>
</thead>
</table>
| Goal(s) of Strategy | - Introduce patients to the network in an efficient manner that builds on existing, trusted relationships  
- Encourage registration for the CIRCLE Newsletter, and thereby increase exposure to the work of the network  
- Disseminate the work of network patients and stakeholder groups |
| Key Features & Functions | - Center-based patient outreach  
- Efficient, tablet-based registration  
- Integration between tablet sign-up and newsletter dissemination  
- Tablet sign up triggers network outreach to new registrants  
- Biweekly e-newsletter with patient-centered content and links to the full ICN website  
- Website with patient-/family-centered content  
- Provides lay research summaries approved by patient/family reviewers  
- Provides downloadable tools and resources developed for patients by patients  
- Mechanism to sign up for opportunities to volunteer as a network collaborator (Patient Advisory Council, Parent Working Group, etc.) |
| Returning Value Approach | - Empowers patients and families to participate directly in the research process  
- Empowers patients and families to share lessons learned about living with IBD with each other  
- Provides a feedback loop to the ICN patient community regarding completed research relevant to their needs and priorities  
- Provides access to toolkits and resources for supporting the patient journey |
Digital Strategies for Returning Value to Research Participants

Research Opportunities: Links to participate in ongoing research studies for which they might be eligible.

- Volunteer Opportunities: Sign-ups to indicate interest in volunteering for the PAC, PWG, or another group that invites patients and family members to serve alongside researchers and clinicians as collaborators.

- Tools: Toolkits and other resources developed by patients to support others in their patient journey.

The website offers a diverse array of content intended to deliver value by returning results in an accessible format, providing resources to help patients and families better manage their journeys, and empowering patients and families to contribute to research as participants and partners in whatever way works best for them.

Implementation Experience. The tablet intervention for ICN’s digital engagement pipeline, funded by the Clare Foundation to build on work established by both Clare and PCORI, was launched as a pilot in first in 2018 with the first of two participating ICN centers and has since expanded to an additional four sites. The approach blended the important influence of patient-provider interactions with the ease and efficiency of combining awareness with registration processes that can occur in-office and in real-time. Existing, trusted relationships between care providers and patients served as the vehicle for raising awareness about the network’s supply of tools and resources, with the goal of better providing support for (and expanding knowledge-sharing among) IBD patients.

To evaluate success of the intervention, the network tracked monthly metrics including the number of newsletter registrants, number of blog views, newsletter click-throughs, and other related data points. The impact of the shift from flyer to tablet usage in August 2019 is clear in the number of newsletter registrants as shown in Figure 12. The network also captured positive anecdotal feedback from network participants, indicating a preference for this updated mode of outreach.

Once new registrants were identified, the engagement team conducted direct outreach inviting patients to consider deeper involvement with the network. The group observed that once patients had exposure to network resources, and could see how openly and collaboratively peers engage in related activities, they were more inclined to personally contribute – in order to increase their own knowledge and to connect with the broader community.
While the tablet intervention demonstrated initial success and produced measurable improvements in registration when compared to the prior paper-based method, complications associated with the COVID-19 pandemic ultimately forced some centers to switch back to the original process. This was done to avoid multi-person use of a touch screen device, in accordance with recommended public health guidance for mitigating spread of the virus. Additional questions about the feasibility and sustainability of the intervention emerged as providers switched to hosting primarily telehealth appointments. Despite the inability to use the tablets during this time, the newsletter registration conversations were maintained as integrated elements of post-visit follow-up discussions, and the network still observed a steady increase in the number of weekly CIRCLE sign-ups. This may be correlated with various factors including, for example, the severity of needs facing patients who chose to seek care during the pandemic. The consistent rise in registration might also be a function of the clinical team’s increased awareness of, and familiarity discussing, ICN’s work and resources over time. Conversations continue regarding the best way to roll out components of this intervention across ICN care centers, particularly in the uncertain time of COVID-19.

Moving forward, gathering and synthesizing data in systematic ways might offer further insights into ways the network could leverage tools and technologies to support future network engagement. To that end, ICN is exploring new ways to combine these separate, but related, digital engagement activities into a single quality improvement framework. Looking at the activities as part of a continuous approach to engagement will offer the scaffolding for a more cohesive and comprehensive evaluation of current activities.

**Lessons Learned.** Through this intervention, ICN demonstrated that digital tools can provide a mechanism of returning value to patients via the efficient integration of network introduction and information sharing activities (which directly benefit the patient) with existing clinical encounters. The choice to partner with trusted clinics and care providers lent credibility to their content, which may have helped to address potential registrants’ concerns about the viability of resources that might have seemed less readily trustworthy if encountered outside of a clinical setting.

One important feature of this intervention was the team’s commitment to finding ways of demonstrating sensitivity to not only the needs of potential network members (patients) but also of clinic providers and staff. ICN intentionally provided tablets that could be loaded with other applications commonly used as part of the clinical encounter, so that providers could initiate questions about newsletter registration without having to switch between devices. Preloading the tablet (and advocating for its use, instead of paper resources) significantly cut down on clinic time spent implementing registration activities; it can be expected that these considerations contributed to the strength and sustainability of this intervention.

This initiative helped to demonstrate one way that ICN leveraged a strategy based on human interaction complemented by use of a digital facilitating tool to deliver content. It is important to acknowledge that these tools do not completely replace, but they rather complement, human interactions. As foreshadowed by this effort, hospitals and health centers may increasingly rely on telehealth technologies to connect with patients. As virtual appointments become increasingly common, the network, and indeed the field, may need to consider ways to further utilize these digital approaches as important extensions of human interactions.
PARTNERS: Web of Engagement App Development Survey

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About the Network. The Patients, Advocates and Rheumatology Teams Network for Research and Service (PARTNERS) Patient-Powered Research Network (PPRN) is a consortium-based partnership between patient advocacy groups (Arthritis Foundation, CureJM, Lupus Foundation of America), an investigator-sponsored research group (The Childhood Arthritis and Rheumatology Research Alliance [CARRA]), and a quality-improvement group (The Pediatric Rheumatology Care and Outcomes Improvement Network [PR-COIN]). The network brings together a community that includes children with juvenile idiopathic arthritis (JIA), childhood-onset systemic lupus erythematosus (cSLE), and juvenile dermatomyositis (JDM), their families, and other key stakeholders with the aim of improving the lives of children with rheumatic diseases. The PARTNERS patient registry is currently comprised of more than 13,000 individuals and the network aims to expand further, with a goal of creating a patient-centered learning health system in which participating members and groups benefit from complementary perspectives, shared infrastructure, and collaborative sharing of expertise and lived experiences in pediatric rheumatic diseases research.

PARTNERS’ patient-centric engagement model reflects the PPRN’s commitment to involving patients and caregivers in leadership, governance, and decision-making activities; our aim is to ensure that research in pediatric rheumatology is patient-centered: relevant to patients and families, feasible for participation at all levels, and committed to providing results to all stakeholders in language understood by all. Achieving patient-centeredness requires ensuring that engagement activities are targeted to the needs of PARTNERS’ stakeholders. We therefore define three categories of stakeholder roles involved in research engagement:

- Patient subjects: Patients, family members, and caregivers contributing personal or proxy data
- Patient partners: Patients, family members, caregivers, and other advocates participating in the conduct of research as co-investigators or as partners in research prioritization, study design development, and study implementation
- Stakeholder partners: Constituents involved based on professional, rather than personal, experience (e.g., clinicians and research investigators)

PARTNERS embeds patients and stakeholders as collaborators on all project tasks in all research phases. Stakeholder guidance, direction, and oversight are key tenets of the network; PARTNERS consistently seeks input and feedback from stakeholders to achieve this mode of network operation. PARTNERS directly gathers information via stakeholder surveys and social media interactions. In order to incorporate and accommodate inclusivity and diversity of stakeholders, we systematically involve patient partners alongside other stakeholders in the design and review of all PARTNERS-generated materials to ensure inclusive language and accessibility for individuals with varying levels of health literacy.

About the Tool. PARTNERS is currently involved in the development of a “Web of Engagement,” which is a network of mobile applications (apps) facilitating information sharing between patients, along with families/caregivers, and PARTNERS organizations. The goal of this approach is to more fully, meaningfully, and holistically engage patients and caregivers in research participation through content personalized to their needs and interests, providing a ‘safe space’ for engagement. We also view this as an opportunity to provide a model of engagement, purpose-built to enable varying levels of engagement over time, recognizing that stakeholders have careers, families, and are dealing with chronic illness. The Web of
Engagement apps should therefore provide a framework to engage even when 'life gets in the way,' empowering users to readily limit or expand their level of engagement on a flexible basis and providing opportunities for research engagement that suit their preferences for doing so at any particular time and context. In order to develop and pilot this app infrastructure, PARTNERS first sought to survey stakeholder preferences and priorities related to the policies and content of this resource. The current case study focuses on the development and implementation of the 'Web of Engagement' design survey.

Survey Content
Survey development was informed by PARTNERS study team members, including all levels of stakeholders and patient partners recruited for the overall project, who first underwent an individual onboarding and training process previously designed and utilized by PARTNERS for other projects. Next, a series of group learning sessions were conducted virtually by a skilled preceptor to provide training in a design process rooted in Agile methodologyi. Over the course of five months, study team members provided feedback on survey content areas, question phrasing, and instrument structure. During and between virtual online design sessions, study team members piloted different question formats (e.g., ranking questions, thought exercises) and discussed aspects of the anticipated survey respondent experience (e.g., survey completion time). To accommodate team members’ availability, PARTNERS offered several participation opportunities, with larger as well as smaller group meetings, including dedicated patient partner focused meetings. Activities also included pre-meeting “homework” activities, with the intent of fostering additional avenues for content and process engagement.

The result of the design process was a 10-minute survey targeting potential future end-users of the web of engagement. Survey questions were directed at gaining first-hand knowledge, across the widest spectrum of participant sociodemographics, about two principal areas that guide the design, policies, and governance of the Web of Engagement:

1. Research engagement topics of interest for those affected by pediatric rheumatologic diseases and their prioritization,
2. Preferences, concerns, and prioritization regarding use and sharing of personal data, including personal health data, contributed by app users.

Survey Tool & Dissemination
Following exploration of various electronic survey options and formats, the final survey was implemented using Qualtrics online survey software (Qualtrics, LLC, Provo, UT), which enabled implementation of desired survey logic and branching, while also providing a utilitarian user experience across desktop and mobile interfaces. Three separate surveys with survey-specific hyperlinks were constructed to enable data collection and tracking for the participating PARTNERS advocacy groups (The Arthritis Foundation, CureJM, and Lupus Foundation of America). Each group agreed to leverage their respective existing dissemination

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### Table 11. PARTNERS Web of Engagement App Development Survey

| Overall Project Aims                                                                 | - To engage patients and caregivers in research participation through content personalized to their needs and interests  
| - To provide a ‘safe space’ for engagement in research  
| - To provide an app-based mechanism tailored to accommodate research engagement when ‘life gets in the way’ |
| Goals of Tool                                                                         | - Garner end-user input across the sociodemographic spectrum to inform development of a community of patient engagement apps  
| - Obtain real-world preferences and priorities for content and policies governing content curation, data sharing and privacy  |
| Key Features & Functions                                                               | - Iteratively-designed end-user survey, based on the feedback of PARTNERS stakeholders  
| - Mobile- and desktop- friendly Qualtrics survey implementation to allow flexibility and accessibility  
| - Diverse dissemination channels, including websites, e-newsletters, emails, and social media  |
| Returning Value Approach                                                               | - Empowering patient partners as leaders, as well as participants, in driving survey design and dissemination to ensure relevance and inclusivity of survey items for survey respondents  
| - Empowering a spectrum of patient partners to inform the design principles and implementation of Web of Engagement framework, so as to ensure the relevance, utility, security, and usability of the Web of Engagement  
| - Design of prototype Web of Engagement community apps to foster research engagement personalized to maximize individual participant relevance, utility, and impact, as well as overall value to the larger research effort and community |

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i Agile Manifesto, Copyright 2001: Kent Beck, Mike Beedle, Arie van Bennekum, Alistair Cockburn, Ward Cunningham, Martin Fowler, James Grenning, Jim Highsmith, Andrew Hunt, Ron Jeffries, Jon Kern, Brian Marick, Robert C. Martin, Steve Mellor, Ken Schwaber, Jeff Sutherland, Dave Thomas. See [https://agilemanifesto.org](https://agilemanifesto.org)
channels to advertise the survey and recruit respondents, including advertising the survey through websites, e-newsletters, emails, Facebook pages, and other social media platforms. In addition, individual patient partners leveraged their own social network and media accounts to boost survey awareness and responses. The survey collected responses for an initial period of one month that was extended to allow additional response collection for particular advocacy groups.

**Design and Implementation Experience.** As described above, patient partners were central to the design of the survey. One of the most influential areas of input was rewording complex questions to ensure relevance for respondents. The survey design group experienced challenges related to managing competing scheduling priorities among members. In order to accommodate this additional sessions and communications were provided. The survey design group also provided feedback that portions of the online Agile-process training sessions were overly technical and didactic. PARTNERS revised the training for subsequent sessions, with plans for adapting the content and presentation of such training for future PARTNERS’ efforts.

Survey dissemination was led by the three affiliated advocacy groups of the PARTNERS consortium, leveraging their existing communication channels, such as email communications, newsletters and social media. The organizations disseminated the survey to individuals already engaged in the pediatric rheumatologic disease community. In working with the advocacy groups’ communications teams, it was important for the project team to (1) ensure that survey planning was included among each advocacy group’s agenda and set of priorities; and (2) dynamically adapt to each organization’s internal timelines and priorities for stakeholder communications.

PARTNERS received usable responses from 586 individuals (Arthritis Foundation: 139; CureJM: 134; and Lupus Foundation of America: 313). Respondents varied across several key demographic dimensions such as age, disease association, and relationship to disease condition; race and ethnicity self-report was not solicited in this survey but is anticipated to be included on future surveys. PARTNERS project members are now analyzing survey results to inform and prioritize Web of Engagement app development and draft policies regarding privacy, sharing, and curation of app content. Preliminary findings include real-world priorities of prospective end-users regarding research engagement app functionality (Figure 13) as well as data privacy and sharing (Figure 14).

In addition to completing the survey, over 50% of respondents indicated interest in receiving information regarding the survey results. Moving forwards, PARTNERS will return survey results to provide a feedback loop and keep respondents informed regarding how their responses have informed the design and policy-making process. PARTNERS also plans to follow up with interested respondents and more members of the community to obtain additional feedback and follow-up questions, particularly regarding interpreted priorities and future areas of interest (e.g., policy considerations, app usefulness and usability). Many survey respondents offered feedback indicating satisfaction in sharing information about their priorities and perspectives.

**Lessons Learned.** The processes of iterative and inclusive survey development and implementation described in the PARTNERS case study highlight the benefits of using a multifaceted, agile-process engagement model. The involvement and inclusion of patient partners on all project teams, including leadership by experienced patient partners, as well as informed use of digital tools and online collaboration technologies, was crucial to the success of the effort. We anticipate that continued application of these approaches will help the PARTNERS’ project team to ensure the relevance of the Web of Engagement design and its pilot implementation, providing utility to the broader patient community in ways that align with their individual goals, needs, and preferences.
Figure 13. Patient priorities for Web of Engagement App functionality.

Figure 14. Patient priorities for Web of Engagement App privacy.
PRIDEnet: Research Dissemination Plan & Auxiliary Tools

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About the Network. PRIDEnet is a national network of sexual and gender minority (SGM) people, including members of the lesbian, gay, bisexual, transgender, and queer/questioning (LGBTQ+) communities, guided by the mission to foster participation of LGBTQ+ people throughout all phases of the clinical research process. The network is led by a team at Stanford University School of Medicine in partnership with 32 health clinics and community-based organizations (PRIDEnet Community Partner Consortium). The network conducts a longitudinal study of the physical, mental, and social health LGBTQ+ adults called The PRIDE Study (pridestudy.org). Through PRIDEnet’s extensive network of partnerships, PRIDEnet works to increase LGBTQ+ participation in research and counter the forces of social stigma, discrimination in health care, and exclusion from clinical research often experienced by these communities.

PRIDEnet’s overarching aim is to involve LGBTQ+ people in the research process, and the network offers a variety of mechanisms to achieve this. One of the network’s driving initiatives is The PRIDE Study—the first long-term national health study focused specifically on the mental, social, and physical health needs facing LGBTQ+ communities. This is an opportunity for LGBTQ+ people to participate in research specifically addressing their needs and priorities. Beyond providing members with access to research with inclusive eligibility criteria, PRIDEnet also offers avenues for constituents to participate as partners in the research process. The network is governed, in part, by the Participant Advisory Committee (PAC), an 11-member multi-stakeholder group of health care specialists that meets monthly to advise on PRIDEnet’s activity, review Ancillary Study applications for The PRIDE Study, and provide feedback on network and study materials and priorities. In addition to this deeply engaged set of stakeholders, the network pursues further routes to extend its reach among constituents. For example, PRIDEnet has used an iPhone app to survey constituents’ research priorities and has conducted community listening sessions to learn about the experiences, needs, and priorities of LGBTQ+ people to ensure the research being conducted is responsive and resonant. Doing this requires a thoughtful approach, conducive to building trust among members as well as between members and the broader research enterprise. This necessary relationship-building often depends on open, bidirectional, and transparent forms of communication. All of the network’s community engagement channels and activities are designed and developed in accordance with PRIDEnet’s established core values (Figure 15).

Figure 15. PRIDEnet core values.

- **Low Burden**
  - We make it feasible to engage with us

- **Easily Accessible**
  - We make it easy to find us

- **Community Engaged**
  - We employ participant input at all stages

- **Participants Know Best**
  - We use feedback to make iterative changes

- **Give Back to Community**
  - We disseminate what we learn

By centering the network’s activities on LGBTQ+ people, PRIDEnet aims to return value by (1) generating research and insights that support the health and wellbeing of LGBTQ+ people, and (2) raising the visibility of the needs and interests of this long underserved and understudied population. This includes being strategic about how best to foster deeper awareness about important aspects of members’ lifestyles and lived experiences within, but also beyond, healthcare contexts. Instead of considering constituents as part of one homogenous stakeholder group, PRIDEnet must account for the fact that, for example, members who identify as transgender women of color may have drastically different needs relative to members who identify as cisgender men who have sex with men (MSM). Additionally, many members need support with health-related issues and interests extending beyond their sexual behaviors or orientations—such as obesity or diabetes. Therefore, in deter-
mining how best to develop and disseminate a cadre of high-quality resources, PRIDEnet staff consider many aspects of constituents’ lives. The network’s aim is to always return results, information, or other forms of value in ways that specifically reflect members’ personhood and honor their identities.

About the Tool. The PRIDEnet team invites external researchers working on academic or community-based projects related to LG-BTQ+ health to apply to work collaboratively with them. In building the infrastructure to manage an ancillary research portfolio, the team has developed numerous resources to inform and support ethical and effective conduct of community engagement activities by researchers seeking to partner with the study (pridestudy.org/collaborate). To guide those who have never received training in community-engaged research, PRIDEnet offers a community engagement primer, which prompts ancillary researchers to consider how they might go about collaborating with partners and sharing information back with the community. To ensure that these materials (including mandatory lay summaries of study proposals and results) reach intended audiences, PRIDEnet developed a Research Dissemination Plan, which is publicly available online in the form of a PDF. This resource, titled “Closing the Loop: A Plan for Disseminating the PRIDE Study Research Results Back to LGBTQ+ Communities,” is presented as a guide that research partners can use to inform their dissemination strategies in accordance with PRIDEnet’s core values. The plan, along with its auxiliary digital tools, is presented below and described in Table 12.

Research Dissemination Plan

In all of its application materials and other resources, PRIDEnet incorporates language that reinforces the primacy of robust and meaningful community collaboration as an important and necessary part of its work. Among other resources provided in the packet of application materials, the Research Dissemination Plan helps to establish the tone for those newly joining the PRIDEnet community. This resource, developed over the course of a year and a half and finalized in December 2019, delivers on the network’s promise of returning insights and information to PRIDEnet constituents in an accessible, relatable manner. It serves the dual purposes of informing partner research teams of the network’s thoughtful and rigorous standards, and of providing actionable guidance to inform development of their respective dissemination strategies. Resource content is presented in several sections:

- Introduction to “The PRIDE Study as Community-Engaged Research” and “The PRIDE Study’s Commitment to LGBTQ+ Communities”
- Information about the “Research Dissemination Vision” and Guidelines
- Description of “How The PRIDE Study Research is Conducted”
- Detailing of “The PRIDE Study Research to Community Dissemination by Stage” Process

This content provides detailed instructions that ensure new research partners understand what is expected of them (e.g., “Ancillary Study investigators must develop a community-level description of the research”), and what kind of support they can expect from the network (e.g., “access to communications templates and guidance in developing additional dissemination materials” and the “opportunity to receive feedback from the PRIDEnet PAC about their community summaries of findings”). It also offers strict guidance related to how results should be communicated back to participants (e.g., “The most historically marginalized and under-represented LGBTQ+ sub-communities receive tailored research results dissemination first (when feasible);”) and where research findings can be published (e.g., “Research results should be published in a journal that is either 100% OA [open access] or has an OA option.”). Further, in alignment with the network’s commitment to transparency and adopting community engagement best practice, the resource provides examples of how different types of audiences and task leads can expect to be engaged at each stage of the dissemination process (Figure 16). For each study, once the data are analyzed and the manuscript is in its final stages, the network collaborates with researchers to determine how best to act on the dissemination plan. In short, this document offers very concrete instructions to guide both the initial development and ultimate implementation of research teams’ dissemination strategies.

Figure 16. Dissemination Plan Excerpt: Research Stage Roles & Activities.
A key requirement of ancillary researchers is that at the end of their study they must provide a 1- to 2-page description of their findings, written in community-friendly language and focusing on results relevant to policy or care provision. PRIDEnet requires this summary by the date of the researcher’s formal publishing, so that the summary can be shared with the study participants and PRIDEnet community prior to or simultaneously with scientific publication. By publishing these guidelines openly on its webpage, PRIDEnet demonstrates its commitment to transparency in its approach and offers its constituents a set of principles and practices to which the network may be held accountable—creating a more equitable power relationship between the research team and its diverse stakeholders.

**Ancillary Research Application Portal**

The Dissemination Plan is bolstered by a set of digital tools and strategies to facilitate its implementation. First, the requirement that ancillary researchers develop concrete plans for community dissemination is enacted through PRIDEnet’s ancillary research application. To have a collaborative research idea considered, investigators must submit a full application through a web-based portal. In addition to capturing information related to the proposed study’s hypothesis, design, regulatory considerations, and funding, the application also collects detailed information about community engagement plans, including the community dissemination plan (Figure 17).

As an indicator of the weight given to this component, information about community engagement is collected at the beginning of the application and includes:

- How the proposal was informed by LGBTQ+ community input;
- Plans to engage LGBTQ+ community members in the research process;
- Brief abstract of the study written in community-friendly language, free of jargon and at a 12th-grade reading level;
- Brief summary of the anticipated experience of someone participating in the study (length of time required, potential emotional impact, etc.);
- Community dissemination methods—a checklist of potential dissemination channels;
- Brief summary of the rationale for the selected dissemination methods.

Applications are submitted electronically through the portal and reviewed by the PAC as well as PRIDEnet’s Research Advisory Committee (RAC), a group of five clinician-researchers who lead the planning and conduct of research activities. Notifications of decisions are sent electronically to submitting researchers via email.

Notably, members of the PRIDEnet team often meet with ancillary study investigators before and as they are preparing their proposals to answer questions and provide additional guidance. After PAC and RAC approval, the relationship between PRIDEnet and ancillary study investigators is a collaborative partnership. Each ancillary investigator is assigned a RAC member as their primary contact to discuss their project, questions that arise, etc. As manuscripts become drafted, they are also sent to the RAC liaison for review and eventually on to the entire RAC (and sometimes PAC members are involved) prior to journal submission.

**Community Summary & Dissemination Channels**

The required community-level research summaries serve as one important mechanism for returning on the network’s commitment to transparency and accessibility for the benefit of network members and others in the broader LGBTQ+ community. Once research is completed, community-level summaries of results must be drafted for review. Per Research Dissemination Plan guidelines, the summaries (written at an 8th-12th grade reading level) should offer the following information:

- Why was the study done?
- What did the research team do?
- What was innovative about this work?
- What did the research team learn?
Digital Strategies for Returning Value to Research Participants

• Why does this work matter to PRIDE communities?
• What are the next steps or activities, related to this study?

Once investigator lay summaries undergo review by PRIDEnet’s Community Engagement Director and Communications Specialist, they are shared with community constituents via email, blog posts, physical research summary flyers, or other formats. The final lay summaries are intended to be released as close to the publication date as is possible; they are first shared with study participants, then disseminated more broadly in diverse formats. A complete listing of all approved ancillary studies, along with their community summaries, is available via a link on the Collaborate page (pridestudy.org/collaborate).

Beyond sharing this information with constituents through the routes mentioned above, PRIDEnet also chronicles all of the research results on its Research Page (Figure 18; https://pridestudy.org/research), which offers links to relevant citations and/or full manuscripts. Currently, features are documented here for each of the nearly 10 studies that have already been published. These are organized chronologically and the page can only be searched manually; however, when new findings are published on the page, a “lightbulb” activated inside the participant portal makes network members aware of the new content. As implementation continues, stakeholder feedback will be used to guide future site improvements that will make the page more user-friendly and easily navigable as more study features are added.

It is also notable that the top of the page includes a link to a video explaining how research questions are identified and translated into research studies, as well as a link to the Research Dissemination Plan. These components offer important contextual value for community members to better understand the research process, why the studies being summarized were conducted, and what the study team’s approach to closing the loop with the participant community is. Here again, there is opportunity for community members to hold PRIDEnet accountable to their dissemination plans in addition to accessing the results.

Implementation Experience. The Research Dissemination Plan was developed over a year and a half period and finalized in December 2019. The plan was developed using the team’s in-house experience about community engagement best practices. The draft plan was reviewed by all team members with multiple drafts and iterations to define the audience, purpose, and role of each team member in the various plan’s components. Because there are several dissemination “products,” it was important for the roles and responsibilities to be clearly defined in order to avoid dropping any balls, etc.

Due to the recent rollout of the plan, the network has not yet pursued a systematic evaluation of its success. However, the network invites feedback from constituents and key stakeholders on an ongoing basis. Publication of research summaries has generated responses from the community, expressing either interest or criticism with different findings—suggesting the intended audiences are indeed able to successfully access these materials. Moving forward, PRIDEnet aims to find ways of gathering quantitative information to assess the reach and impact of its dissemination activities. For example, to potentially guide future efforts, the network is currently tracking traffic on its Research Page.

Despite having not yet conducted a full-scale evaluation of guided dissemination activities, PRIDEnet has received anecdotal feedback. PAC members have acknowledged the importance of the Research Dissemination Plan and associated resources for sharing results back to the community. Separately, some ancillary research leads expressed that they had not expected PRIDEnet to provide such hands-on collaboration or oversight over the process. Community-engaged research is new to many of these investigators, and they had not realized they would personally need to climb such a steep learning curve in order to comply with the standards for meaningful engagement set by PRIDEnet. Others expressed surprise, and even impatience, with the time needed to support
PAC/RAC review of summaries as well as the requirement that results be disseminated in a sequenced fashion with participants first. This sequencing is an important message to participants that the research is being conducted as a result of their partnership and contributions, and thus they have a right to priority access to findings. At the same time, this approach can be in conflict with traditional investigator mindsets that are often eager to disseminate findings as far and wide as possible without attention to priority sequencing. The level of oversight required to do this well, on the part of ancillary researchers as well as PRIDEnet, provides evidence that the existing research enterprise is still not conducive to (or equipped for) thoughtful community engagement or dissemination activities. Compressed timelines and a sense of scarcity, as modeled by academia, can lead even willing investigators to conclude that there is insufficient time to fully and/or properly engage partners in research activities. To counter this impression and facilitate effective engagement, PRIDEnet has created a flowchart to guide partnered research interactions by aligning systems and schedules across stakeholder groups. This is just one way the team demonstrates that building in time for thoughtful engagement can ultimately help the work to progress faster, even if it requires more intentional initial planning. Ultimately, though, researchers will only buy into a community-engaged model if they (1) have guidance on how to do so effectively, and (2) have an experience that demonstrates some kind of returned value or increased impact as a result of engagement activities.

Lessons Learned. One key feature of the research landscape that will continue to affect uptake of thoughtful, community engagement-oriented dissemination approaches is the role of leading funders. As PRIDEnet staff and partners have discovered, intensive and intentional dissemination activities require dedicated time, money, and effort. If the norm in the field continues to deprioritize dissemination activities, it is unlikely that research teams will dedicate the amount of resources needed to do this work in ways that align with the high standards adopted by PRIDEnet and celebrated by its membership. Providing allocated funding to support these...
kinds of specialized and community-centered dissemination activities can help to better hold researchers accountable, guarantee the quality of research products, and render these outputs more useful and usable for the field.

Beyond increasing funding inputs to support this work, increasing the scale and scope of community engagement inputs can also help to bolster the scientific impact of research conduct and dissemination activities. While infusing the work with partner and participant perspectives can help improve research relevancy, this level of engagement can also be difficult to secure. Digital tools and resources can increase the scale and spread of both community engagement and dissemination efforts, but connection and communication can prove difficult across solely digital channels. As such, it becomes crucial to ensure that core elements of human relationships and personal interactions are mirrored or amplified even in virtual contexts. For this reason, among others, PRIDEnet’s approach offers a useful model for returning value to partners and participants by:

- acknowledging the importance of people's personal identities, perspectives, and contributions;
- helping people to “see themselves” in the work of the network and the communities it supports;
- demonstrating a commitment to protect and honor people's contributions of sensitive information;
- communicating with stakeholders in ways that enable and invite their feedback;
- committing to share results, information, and resources in ways that reflect end-users’ needs and values;
- requesting input and creating open channels for bidirectional exchange; and
- creating resources that not only instruct, but also educate and advance the field.

Moving forward, the network seeks to continue returning value by pushing the boundaries and to move beyond the current approaches to dissemination of static content by embracing increasingly digitized models of engagement and dissemination. Ultimately, PRIDEnet hopes to explore new digital tools and technologies, such as video-based applications, that are uniquely responsive to the emerging needs and interests of the LGBTQ+ community.
PRINCIPLES FOR RETURNING VALUE

The literature scan and case studies offer insights into the emerging approach of returning value to research participants and the use of digital tools/strategies to facilitate that delivery. This approach seeks to address persistent challenges in the research enterprise related to poor recruitment and retention as well as a broader erosion of public trust in scientific institutions. Returning value is one way researchers can work to develop productive and lasting relationships that lead to a virtuous and mutually-beneficial cycle of research engagement. This approach demonstrates appreciation for participants’ unique contributions to a study, illustrates their impact on the work, and acknowledges their dignity as independent partners in the research process. At the same time, it establishes the trustworthiness of researchers and strengthens the credibility of the research enterprise more broadly. In developing policies and practices to deliver value to participants, the DEWG recommends adherence to the following guiding principles:

• **Participant-centered**: Researchers should pursue approaches that will be valued from the perspective of the participants. This requires understanding what it is that participants value most as well as understanding their accessibility needs and preferences to ensure delivery is effective.

• **Broadly Defined and Multi-faceted**: Value should be defined broadly to include but extend beyond the traditional approaches of compensation and aggregate study findings. This could include individualized and/or contextualized study results, educational resources, skill-building tools/resources, opportunities to engage with researchers or in the research process, opportunities to engage and build relationships with other participants, among other approaches. Because different participants will prefer value in different forms, and because the ability to deliver certain types of value may be time dependent, researchers should pursue multifaceted strategies that deliver value in multiple forms.

• **Timely and Ongoing**: There are often significant lags between the time when a participant contributes data and when the results have been analyzed and disseminated. Sharing results in a participant-centered way as close to the time of scientific publication as possible is important, but researchers should explore other ways to deliver value closer in time to the act of participation in order to demonstrate appreciation for contributions. Researchers should also consider opportunities to deliver value on an ongoing basis to maintain relationships with participants over time.

• **Accessible**: The method of value delivery should ensure all participants have access and can benefit. This means the content and the method of delivery must be readily available, perceivable, understandable and acceptable to participants. Given the diverse needs and preferences of different participants, researchers may need to explore multiple avenues of delivery to reach everyone.

• **Effective**: Researchers should seek to ensure that value delivered is, in fact, received by participants. Research teams should assess their own effectiveness by evaluating and measuring activities, outcomes, and impact.

The use of digital tools and strategies to support delivery of value, while not a panacea, can facilitate many of the guiding principles outlined above through the mitigation of barriers related to cost, scale, speed, and accessibility. As new tools are developed, and research teams adapt tools from other fields and/or social settings, increased use of digital approaches could accelerate the research community’s adoption of a mutually-beneficial approach to researcher-participant relationships.

CONCLUSION

The inability to recruit and retain a sufficient number of participants in research studies remains a persistent challenge with severe consequences. This problem leads to canceled projects, costly delays, and jeopardized internal and external validity—all of which translates into gaps and delays in the discovery, dissemination, and uptake of effective interventions that enhance care and improve patient lives. If the medical and health services research enterprise is to address this challenge, it is imperative to approach the researcher-participant relationship as more of a bidirectional partnership and find ways to deliver value in return for participation. The majority of participants expect to receive study results, and they find value in a range of resources and activities. Researchers should work to incorporate policies and practices for returning value that are participant-centered, broadly defined and multifaceted, timely and ongoing, accessible, and effective. Adopting this new approach to the researcher-participant relationship is necessary, but it is not without its own challenges. This will create new demands on the research enterprise, requiring new skills and time/resource allocations from research teams. With the emergence of new entities like PDRCs, research initiatives are beginning to prioritize these approaches. Funders can expand and accelerate this evolution through proposal and reporting requirements as well as specific budget allocations. In addition, the development and adoption of digital strategies for returning value can help mitigate some of the barriers related to cost, scale, and time. As more organizations and research teams implement value-based relationships with participants, the enterprise’s collective experience with effective, inclusive approaches will become increasingly available. Longer term, there will be need to shift from exploration to evaluation of value delivery methods so that research teams can select approaches and tools based on best practices for given implementation contexts.
APPENDIX I: DIGITAL ENGAGEMENT

SCAN FINDINGS

Scan Findings

The scan resulted in a set of ten examples meeting the inclusion/exclusion criteria outlined above. While the scan provided evidence that researchers are exploring increasingly creative ways to leverage digitally-enabled solutions in their work, the tools and methods identified tended to align with three main functionality types:

1. Returning results: individual and/or aggregate results of completed or ongoing studies with contextual information and/or opportunities for participants to engage more deeply with the content (number of scan results = 3).

2. Building capacity: training modules to prepare patients to be research participants/partners (number of scan results = 2).

3. Cultivating community: creating virtual spaces and/or opportunities for resource/knowledge sharing, communication, and collaboration (number of scan results = 5).

Below, each functionality type is summarized followed by each related result from the scan, outlining the goals of the overarching project or initiative, the goals of the digital tool, key features and functionality of the tool, and the potential value provided to research participants.

Returning Results

One of the most fundamental uses of digital tools to return value to research participants, as previously noted, is to support the provision of individual or aggregate results. Digital platforms offer an approach that can scale easily for the creation and distribution of personalized reports that contextualize an individual’s results as part of the broader study or by tying in additional information to aid with interpretation. Such tools can be built into broader participant portals that support a wide range of functionality including enrollment and data collection. Specific examples from the scan are highlighted below.

Digital Exposure Report-Back Interface (DERBI)

DERBI is a platform that has been used by researchers to return value to participants in environmental health studies funded by the National Institute of Environmental Health Sciences (NIEHS), including: the Personal Exposure Report-Back Ethics (PERE) study, the CDC Green Housing Study (GHS), and the Child Health and Development Study.

This platform seeks to return value by honoring participants’ “right to know” their own results related to harmful chemical exposure. Researchers employed user-centered design to develop the functionality, look, and feel that would be most useful to participants. Features emphasize the ability to compare an individual’s results with distributions across the full study, as well as the provision of complementary educational materials to support participant interpretation of results and risk-modifying actions that could be taken in follow-up.

Personal Genome Project (PGP)

Launched in 2005 at Harvard University and now in five countries, the PGP was designed to allow scientists to link human genetic information with medical information and environmental exposure data. To mitigate anticipated challenges related to data privacy and sharing, the project took an open data approach. Participants who join consent to publicly share their genomic and trait data in an integrated, publicly-accessible format. Participants are given access to their unique identifier and have the ability to view their individual research data—including raw data where feasible. Through the participant portal, participants can view their results, link to resources to aid with interpretation or analysis, discover opportunities to engage in citizen science, and make decisions about how much information to share in their public profiles (Figure A2).

MyLymeData Patient Registry and Tools

MyLymeData is the first national large-scale research study of chronic Lyme disease and includes a registry of nearly 12,000 patients. This patient-powered big data project focuses on understanding patient experience, symptoms, and treatment outcomes—and how they change over time. Patients are invited to register and complete surveys periodically to update their information. The system uses digital tools and technologies to pool diagnosis and treatment data, making it easy to identify patterns observed across patients and to anticipate treatments likely to be successful for certain types of patients. The parent organization, LymeDisease.org, works with researchers, clinicians, and others to analyze the data and report findings back to the community through data visualizations, white papers, peer reviewed publications, and other means. A particularly powerful tool for returning results is the MyLymeData Viz Blog (Figure A3) which is made publicly available on LymeDisease.org. It includes a range of interactive graphs and charts that allow the user to hover over portions for more details. In the secure participant portal, patient registrants are able to access their own data and explore how they compare to others in the registry.
### Table A1. Digital Exposure Report-Back Interface (DERBI)

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Support return of results to individuals participating in environmental health studies</td>
</tr>
<tr>
<td>- Empower individual action to lower unnecessary exposure to harmful chemicals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal(s) of Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Present complex chemical exposure data in accessible ways</td>
</tr>
<tr>
<td>- Share individual and aggregate results to enable the participant to compare personal results with those found in the broader research sample</td>
</tr>
<tr>
<td>- Provide participants with guidance on reducing exposure to harmful chemicals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Key Features &amp; Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>- User-centered, interactive design and graphics</td>
</tr>
<tr>
<td>- Digestible, accessible, and personalized results</td>
</tr>
<tr>
<td>- Comparative results analysis</td>
</tr>
<tr>
<td>- Tailored recommendations for lowering harmful exposure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Returning Value Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Provides participants with direct access to their individual research results</td>
</tr>
<tr>
<td>- Allows participants to explore the data and see how they compare to other participants</td>
</tr>
<tr>
<td>- Gives participants actionable information on how to change their own exposure to environmental chemicals</td>
</tr>
<tr>
<td>- Enables participants to increase their scientific literacy by including resources to aid in interpretation of research testing and results</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <a href="#">DERBI: A Digital Method to Help researchers Offer “Right-to-Know” Personal Exposure Results</a></td>
</tr>
<tr>
<td>2. <a href="#">Digital Exposure Report-Back Interface (DERBI)</a></td>
</tr>
</tbody>
</table>

### Table A2. Personal Genome Project Participant Portal

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>- To create public genome, health, trait, and exposure data that can be used in both traditional and citizen science research projects to understand the functional effects of genetic variation and advance personalized genomics and medicine</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Goal(s) of Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Promote open data sharing that inspires and enables new traditional and citizen science research projects related to personalized genomics and medicine</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Key Features &amp; Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Includes education modules and an exam as part of informed consent</td>
</tr>
<tr>
<td>- Offers mechanisms for participants to contribute their own data (medical information, survey responses, etc.)</td>
</tr>
<tr>
<td>- Displays results from all data collection activities (sequencing, surveys, assays, etc.)</td>
</tr>
<tr>
<td>- Displays listings of all projects in which the participant's data have been used</td>
</tr>
<tr>
<td>- Provides links to external resources/tools for data analysis and interpretation</td>
</tr>
<tr>
<td>- Functionality to support participant decision-making about what information is included in their public profiles</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Returning Value Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Renders contributed data publicly available to increase researcher access and maximize use in scientific inquiry</td>
</tr>
<tr>
<td>- Invites participants to contribute additional data they consider important/valuable</td>
</tr>
<tr>
<td>- Provides participants with direct access to their raw data and all the ways the data have been used in research studies</td>
</tr>
<tr>
<td>- Gives participants control over how much information is displayed on their public profile</td>
</tr>
<tr>
<td>- Encourages participants to increase their scientific literacy by providing resources to aid in interpretation of results</td>
</tr>
<tr>
<td>- Invites participants to take on the role of scientific investigator by participating in citizen science projects or exploring analytical tools on their own</td>
</tr>
<tr>
<td>- Gives participants actionable information on how to change their own exposure to environmental chemicals</td>
</tr>
<tr>
<td>- Enables participants to increase their scientific literacy by including resources to aid in interpretation of research testing and results</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. <a href="#">Personal Genome Project UK (PGP-UK): a research and citizen science hybrid project in support of personalized medicine</a></td>
</tr>
<tr>
<td>2. <a href="#">Harvard Personal Genome Project: lessons from participatory research</a></td>
</tr>
<tr>
<td>3. <a href="#">The PGP is Not a Traditional Research Study</a></td>
</tr>
<tr>
<td>4. <a href="#">GenoME mobile application</a></td>
</tr>
</tbody>
</table>
Digital Strategies for Returning Value to Research Participants

Building Capacity

The scan also surfaced an example of tools designed specifically with the aim of building participant capacity (i.e. education/skill-building focus). Digital approaches can be particularly useful in this context by increasing access to valuable educational content, or by presenting that content in interactive and dynamic formats to meet the needs of diverse learners. These types of tools could be used to offer online trainings or educational modules that support self-guided or self-paced learning. The examples provided below represent approaches that could be readily implemented in other contexts with limited tailoring to ensure relevance to the target audience/research participant community.

Table A3. LymeDisease.org’s MyLymeData Patient Registry & Tools

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- Empower individuals with Lyme disease to engage in research, learn from each other, and use research results to improve their lives</th>
</tr>
</thead>
</table>
| Goal(s) of Tool | - Quickly and privately collect, aggregate, and analyze patient data in order to facilitate patient-centered research  
- Better ensure that Lyme disease research findings are used to improve patient care/experience  
- Provide means for Lyme disease patients to learn from each other through data |
| Key Features & Functions | - Patient-centered, big data approach to studying chronic lyme disease  
- Online patient registry that includes secure patient enrollment and contributions of survey-based data  
- Patients have total control of their data contributions and privacy  
- Secure participant portals give enrollees access to their data contributions and comparisons with the overall cohort, incorporating gamification to increase engagement  
- Aggregate results are posted on the MyLymeData Viz Blog in interactive formats with explanatory narrative to contextualize the findings |
| Returning Value Approach | - Created and run by patients, which ensures focus on issues that are particularly relevant and salient to individuals with Lyme disease  
- Leverages digital tools and technologies to expedite data collection and analysis, and to enable the use of big data to glean insights more directly relevant for patients  
- Provides participants with direct access to their individual data contributions  
- Grants patients full privacy and autonomy over their own data  
- Allows participants to explore the data and see how they compare to other participants (secure portal)  
- MyLymeData Viz Blog makes aggregate results publicly available and displays them in an interactive way with explanatory text to contextualize findings and help viewers improve their scientific literacy |
| Source | 1. About MyLymeData  
2. MyLymeData Viz Blog |
Social Media Research Toolkit
The SMART Toolkit was created to orient people to best practices for leveraging existing, familiar social media and networking sites to support engagement throughout the research continuum (Figure A4). In order to build capacity within this community—preparing research partners to serve as full and equal contributors—one of the project partners (the Global Healthy Living Foundation) developed a series of “Research 101” slide decks. Written in lay language, these online educational decks introduce key research terms, concepts, and processes to new stakeholders. One slide in the deck helped to demonstrate the anticipated ways digital platforms would be used to support various research activities, as shown in Figure A5.

The Toolkit itself provides a clear and concise series of steps that can be taken by organizations or entities seeking to engage stakeholders in research or dissemination activities. In order to build the capacity of these implementing groups, the Toolkit (or the SMART User Guide) outlines a chronology of key activities and considerations. Further, the online Toolkit is accompanied by a virtually-hosted SMART Slide Deck that orients people to the already user-friendly tool.

Table A4. Social Media Research Toolkit (SMART)

| Project Aim(s) | - Work with spondyloarthritis (SpA) patients and other stakeholders to develop a toolkit of best practices for social media engagement in health research  
| - Ensure the toolkit is replicable for other diseases or conditions |
| Goal(s) of Tool | - Provide guidance and best practices for patients, health care professionals, and anyone interested in using social media and networking sites (Twitter, Facebook, Instagram, etc.) as a platform for research engagement  
| - Leverage existing tools and platforms to identify patient-relevant research questions, support open clinical dyad discussion, disseminate evidence-based information, and match patients with research opportunities |
| Key Features & Functions | - Developed with input from Technical and Patient Advisory Teams  
| - Applicable for research across a range of clinical conditions  
| - Defines social media and flags opportunities/challenges of using social media to support research  
| - Distinguishes three separate “phases” of social media engagement—before, during, and after research—and provides tailored guidance and best practices for each  
| - Provides “how to” guides and lists key considerations, to inform toolkit application  
| - Includes online documentation, slide decks, and other educational resources |
| Returning Value Approach | - Provides a roadmap for everyday people to gain access to individuals and institutions with whom they may be unlikely to engage otherwise, such as doctors and researchers  
| - Makes complex media engagement strategies more accessible for individuals with little-to-no prior communications training  
| - Facilitates broader engagement of patients in the research and the research process |
| Source | 1. Social Media and Research Toolkit (SMART)  
| 2. What is SMART?  
| 3. SMART: Social Media and Research Toolkit |
Celiac Disease Foundation Patient Advocate Platform

The Celiac Disease Foundation Patient Advocate Platform centers on a set of training modules to prepare patients and their caregivers for future engagement in the research process as partners or participants. It highlights the unique expertise this community has to offer the research enterprise and focuses on increasing knowledge about celiac disease and clinical research so they can participate as informed and effective patient advocates. As shown in Figure A6, the platform also contains tools to connect potential participants to research opportunities, information about ongoing trials, and a mechanism to join the affiliated patient registry. Here, the return of value includes skills- and capacity-building activities that can help community members better understand the relationship between the research enterprise and their own clinical treatment options or outcomes as well as direct access to opportunities to participate.

Table A5. Celiac Disease Foundation Patient Advocate Platform

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- Increase and improve patient-centered outcomes research and clinical trials related to celiac disease to improve the lives of patients and their caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal(s) of Tool</td>
<td>- Educate affected individuals about celiac disease and clinical research, so that they are prepared to participate in research as informed, effective advocates&lt;br&gt; - Facilitate opportunities for patients to join recruiting research studies and a patient registry related to celiac disease and gluten intolerance&lt;br&gt; - Inform patients about current clinical trials related to celiac disease and gluten intolerance</td>
</tr>
<tr>
<td>Key Features &amp; Functions</td>
<td>- Training component includes a baseline assessment, video modules, understanding checks for each module, a final assessment, and a certificate of completion&lt;br&gt; - Access to information about ongoing and recruiting trials/studies, which includes a responsive trial search engine that can limit to specified parameters (e.g., trials calling only for male participants)&lt;br&gt; - Access to enroll in iCureCeliac patient registry by setting up a personalized account and submitting survey data</td>
</tr>
<tr>
<td>Returning Value Approach</td>
<td>- Builds capacity and increases scientific literacy through education about the condition and clinical research&lt;br&gt; - Invites and empowers patients to engage in the research process as participants</td>
</tr>
<tr>
<td>Source</td>
<td>1. Become a Patient Advocate(^{41})</td>
</tr>
</tbody>
</table>
Cultivating Community

Beyond one-way transmission of information in the form of data resources or research results, digital platforms and portals can also support bidirectional exchange within and among researcher and participant communities. Offering shared spaces for communication and collaboration, these Virtual Communities of Practice (VCoPs)\(^37\) can provide the scaffolding for meaningful contributions from engaged participants – while also connecting them to others who may share their lived experience. Similarly, such platforms can strengthen relationships between researchers and participants, which instills mutually-beneficial trust and respect.

NatureNet

The NatureNet technology platform was designed specifically to meet the needs of small community-driven environmental projects (CDEPs). The researchers behind the platform’s development highlight that CDEPs are unique from other types of citizen science in that they are intensely place-based and closely anchored to the geographic, political, and cultural issues of local communities. The authors of the tool were informed by asset-based community development theory and community of practice theory, but ultimately designed the platform in alignment with affinity space theory. The platform needed to provide a common space for people with diverse knowledge and backgrounds to come together and function effectively around a shared common endeavor. It also needed to be flexible to support an ever-changing community ecosystem.

### Table A6. NatureNet Platform

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>Enable community-driven environmental projects in the Anacostia Watershed in Maryland and the District of Columbia</th>
</tr>
</thead>
</table>
| Goal(s) of Tool | Support creation of new projects and design ideas  
| | Provide space for individuals’ data, notes, or project plan storage  
| | Allow convenient cross-collaboration between platform users |
| Key Features & Functions | Multiple channels for participant contribution and communication  
| | Design accounts for diversity of participant skills, needs, interests, cultures, knowledge, time commitment and technical expertise  
| | Interactive elements allow participants to help others, add comments, and “like” design ideas |
| Returning Value Approach | Builds capacity and increases scientific literacy through explanatory content  
| | Offers multiple avenues for participating (e.g., starting a project, contributing to a project, providing feedback)  
| | Provides equalizing opportunities for newcomers and experienced participants to directly govern, lead, partner in, and/or contribute to environmental projects  
| | Confirms value of different sources of knowledge  
| | Builds community and social support by providing mechanisms for participants to directly engage with each other over shared interests |
| Sources | 1. Interaction design of community-driven environmental projects (CDEPs): A case study from the Anacostia Watershed\(^33\)  
| | 2. Nature-net.org\(^4\) |
Open Humans offers a platform that seeks to balance the practical challenges of merging diverse streams of individual-level data with the ethical challenges of mitigating risks associated with sharing personal data. The community-based platform offers resources to accommodate a range of data, such as personal genetic data, wearables, and continuous glucose monitor data, as well as the tools to enable close individual control over personal data access and sharing authorizations. Through additional widgets and tools, the platform seeks to empower individuals to understand and explore their own data as well as providing researchers with the ability to establish new projects.

**Table A7. Open Humans Platform**

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- To create a digital ecosystem to facilitate individual data aggregation across diverse sources, management of data sharing, and co-creation of research</th>
</tr>
</thead>
</table>
| Goal(s) of Tool | - Enable data sharing and exploration projects at individual and group levels for the purposes of education, health, and research  
- Facilitate de novo data collection as well as data uploads/imports from diverse platforms  
- Foster equal opportunity for data exploration across researchers, patients, data scientists, citizen scientists, and the like |
| Key Features & Functions | - Supports a diverse range of data from external sources (e.g. 23 and Me, AncestryDNA, Fitbit Connection, Google Fit, Quantified Flu)  
- Widgets to support creation of de novo data collection mechanisms  
- Tools and resources (including modest funding) to support new project creation  
- Resources and a community forum to support individuals interested in self-research  
- Slack channel to promote community engagement |
| Returning Value Approach | - Builds capacity and increases scientific literacy through annotated analytic and interpretative tools  
- Empowers users to contribute their own data and tightly control how the data are used and shared  
- Connects users to new and ongoing data exploration projects in which they may be interested in participating  
- Invites participants to take on the role of scientific investigator by participating in citizen science projects or exploring analytical tools on their own  
- Provides equalizing opportunities for users from all backgrounds and experiences to directly lead, partner in, and/or contribute to data exploration projects  
- Builds community and social support by providing mechanisms for users to directly engage with each other and other stakeholders |
| Sources | 1. [About Open Humans](#)  
2. [Open Humans: a platform for participant-centered research and personal data exploration](#)  
3. [User Perspectives of a Web-Based Data-Sharing Platform (Open Humans) on Ethical Oversight in Participant-Led Research: Protocol for a Quantitative Study](#) |
Digital Strategies for Returning Value to Research Participants

Second Life Virtual World

Exploring digitally-enabled approaches for mitigating some common barriers to engagement, one team of researchers investigated the extent to which conducting health care and research activities in a virtual world might help to facilitate engagement. The online virtual world (VW) known as Second Life was used as the test environment for this study. This three-dimensional, customizable environment enables people to create and assume “avatars” with a range of both visible and functional limitations (Figure A9). Since the platform is free to use and easily, publicly accessible online – engaged partners were able to participate in spite of characteristics or circumstances that might have otherwise been limiting (e.g., mobility or communication issues). For the purposes of this study, a focus group was conducted in the context of this VW in order to determine the extent to which similar “spaces” might be useful in supporting future engagement in health care and research activities. A similar focus group session is depicted in Figure A10. Ultimately, it was determined that these virtual environments could be helpful in overcoming barriers to research engagement, especially for peer-led work, and in cases when adequate training and/or site support is provided. In these ways, they both help to build the capacity of individual engagement partners, while also cultivating safe spaces and communication platforms that can help to connect people.

Table A8. Second Life Virtual World

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>- Explore the prospect of using 3-dimensional web-based computer-generated environments (or virtual worlds) as a tool to facilitate the involvement of patients and members of the public in research and health care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Goal(s) of Tool</td>
<td>- Provide an online world in which “residents” can create virtual representations of themselves and interact with other people, places, or objects</td>
</tr>
</tbody>
</table>
| Key Features & Functions                                                      | - Offers a variety of modes of communication (e.g., speaking out loud, typing)  
|                                                                              | - Functionality to customize virtual environment according to an individual’s needs (e.g., a therapeutic, relaxed environment for patients who may need it, such as those with psychological disorders and/or terminal illnesses, and the elderly)  
|                                                                              | - Customized avatars—everything about an avatar can be customized, from skin, textures, clothes, body parts, hairstyles, expressions, gestures, etc.  
|                                                                              | - Avatars can explore their virtual world, meet other “residents” (or avatars), socialize, participate in both individual and group activities, build, create, shop, and objects with one another.  
|                                                                              | - Platform is free and publicly available                                                                                                                  |
| Returning Value Approach                                                      | - Removes barriers for engagement in health care for individuals for whom real-life engagement is inaccessible  
|                                                                              | - Increased opportunity to challenge traditional power structures (due to remote interaction)  
|                                                                              | - Leveling of the “playing field” in order to equalize the voices and perspectives of diverse research partners  
|                                                                              | - User-friendly, publicly-available online platform allows for ease in involvement  
|                                                                              | - Offers comfort of anonymity for patients who cannot or do not wish to attend physical support groups                                                                                                                   |
| Source                                                                         | 1. Using virtual worlds for patient and public engagement                                                                                                                                                                                                            |
**Digital Strategies for Returning Value to Research Participants**

**WYRED Project**

The WYRED (netWorked Youth Research for Empowerment in the Digital society) Project, funded in 2016 by the European Union's Horizon 2020 initiative, aims to provide a framework in which children and youth can participate as partners in the research process to explore their questions and concerns related to digital society. The project also seeks to provide mechanisms for children and youth to communicate their perspectives to key stakeholders to influence policy and decision-making. There is strong emphasis on engaging youth throughout all aspects, including governance, the full research life cycle, and translation activities. Inclusion, diversity, and the empowerment of the marginalized are central tenets of this work. The technological base for the project is a web-based platform and mobile app with extensive social media integration to facilitate the high degree of social dialogue the team seeks.

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**Figure A10.** Screenshot showing a focus group session in an environment specifically created to meet the team's virtual research and discussion needs. (Source: Avataric Blog – “A Clever Tool for Second Life Focus Groups” on December 10, 2014.)

**Table A9. WYRED Platform**

<table>
<thead>
<tr>
<th>Project Aim(s)</th>
<th>Goal(s) of Tool</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provide a research framework in which children and young people can express and explore their questions and concerns related to digital society</td>
<td>Enable a participatory research cycle involving networking, dialogue, research activities, and interpretation phases that is centered on and driven by children and young people</td>
</tr>
<tr>
<td>Offer mechanisms for children and young people to communicate their perspectives to other stakeholders</td>
<td></td>
</tr>
<tr>
<td>Produce diverse outputs, critical perspectives, and other insights that can inform policy and decision-making</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Key Features &amp; Functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extensive integration with social media platforms to foster greater inclusion and accessibility</td>
</tr>
<tr>
<td>Functionality for creating and tailoring user profiles</td>
</tr>
<tr>
<td>Interaction spaces that facilitate exchange of messages, videos, and other media in a variety of formats</td>
</tr>
<tr>
<td>A repository for outputs created as part of the dialogue and research processes</td>
</tr>
<tr>
<td>Tools to store, manage, analyze, and visualize (e.g. word clouds) data collected through research projects</td>
</tr>
<tr>
<td>Data security features to ensure the platform serves as a safe space for children and youth to express their views and perspectives without fear, abuse, bullying, etc.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Returning Value Approach</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offers a structured and guided exchange whereby young people can explore and surface their understandings, perspectives, perceptions, and concerns</td>
</tr>
<tr>
<td>Builds capacity and increases scientific literacy through participant engagement in the research lifecycle</td>
</tr>
<tr>
<td>Empowers users to contribute their own data</td>
</tr>
<tr>
<td>Connects children and youth to new and ongoing research projects in which they may be interested in participating</td>
</tr>
<tr>
<td>Empowers children and youth to take on the role of scientific investigator by pursuing projects of interest to their questions and concerns</td>
</tr>
<tr>
<td>Provides equalizing opportunities for children and youth from all backgrounds and experiences to directly govern, lead, partner in, and/or contribute to research projects</td>
</tr>
<tr>
<td>Builds community and social support by providing mechanisms for children and youth to directly engage with each other, researchers, and other stakeholders</td>
</tr>
<tr>
<td>Captures emergent insights in ways that support the translation of youth perspectives directly into research, and ultimately into social and policy decision-making</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Sources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Wyred.eu</td>
</tr>
<tr>
<td>2. Get WYRED</td>
</tr>
<tr>
<td>3. Networked youth research for empowerment in digital society, The WYRED project</td>
</tr>
</tbody>
</table>
Zooniverse

Zooniverse, described as “the world’s largest citizen science platform”, offers non-traditional research partners and participants with multiple mechanisms for engagement in research. In this community, participants are invited to contribute to research and are presented with invitations to volunteer in other relevant capacities. The platform also offers project-building tools that provide tips on how to optimize volunteer engagement, and increase the pathways by which needed data can be sourced. One of the most valued elements of Zooniverse is its capacity for fostering discussion between volunteers and researchers, which often generates some of the most important discoveries.

Figure A12. Screenshots of a Zooniverse project page: engaging volunteers in “Bash the Bug” research on antibiotic resistance.

Questions for the Team

Please set up the forum to allow participants to discuss the bash the bug project. Here we will try every effort to identify the forum and engage as soon as we can.

Please reply to identify discussion.

Suggestion

 Euler_Euler: I am confused whether this is heading towards a bug or not. I thought it is...

Recent Comments

Popular Tags

euler_euler, bash_the_bug, bugscreening...

Question

Oz: am I doing this right? How is it...

Recent Comments

Popular Tags

oz, bash_the_bug, bugscreening...

On Us Question

Anonymous: I have been getting many wrong results. I think the answers in the test.

Recent Comments

Popular Tags

anonymous, bash_the_bug, bugscreening...

Almost done

Anonymous: Please update the bug-screening page. There is no bug and there is...

Recent Comments

Popular Tags

anonymous, bash_the_bug, bugscreening...

22nd May Activity

Anonymous: From what you guys, it looks like we are getting very close to the end of the project...

Recent Comments

Popular Tags

anonymous, bash_the_bug, bugscreening...

Bash the Bug Talk

Bash the Bug Talk — Science

Notes

- Participants: 40, Discussions: 10

Recent Comments

Popular Tags

Science, bash_the_bug, bugscreening...

Technical Support

I have a technical issue or bug, we can help you with our website. Please ask for help.

Recent Comments

Popular Tags

technical_support, bash_the_bug, bugscreening...

Chat

This is where people in our community can chat about the project, and help us.

Recent Comments

Popular Tags

chat, bash_the_bug, bugscreening...

Help

If you are having trouble with your data, you can ask for help here.

Recent Comments

Popular Tags

help, bash_the_bug, bugscreening...

Questions for the Team

I am working on this forum to involve the community in discussing the project. It would mean every effort to discuss. I would like you to answer questions as well.

Recent Comments

Popular Tags

questions_for_the_team, bash_the_bug, bugscreening...

Science

A place to discuss the project and science.

Recent Comments

Popular Tags

science, bash_the_bug, bugscreening...

Figure A11. Screenshots from the WYRED Platform homepage and one “Communities” page.
<table>
<thead>
<tr>
<th>Table A10. Zooniverse Platform</th>
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<tbody>
<tr>
<td><strong>Project Aim(s)</strong></td>
</tr>
</tbody>
</table>
| **Goal(s) of Tool** | - Offer people of all ages and backgrounds opportunities to participate in a diverse array of research projects as partnered citizen scientists  
- Provide researchers with the tools and resources to design projects for success under the citizen science model  
- Provide data to researchers to publish in peer-reviewed publications |
| **Key Features & Functions** | - Interactive discussion boards, where volunteers can communicate with each other and with research teams at project and community levels  
- Efficient integration of discussion boards with other applications, to enable tracking across different modes of engagement (e.g., hashtags, comments, project plans) in order to facilitate more complex tasks such as collaborative analysis  
- Transparent space for communal conversation regarding Zooniverse-wide topics (e.g., policies, governance)  
- Widgets to design project plans, data collection forms, etc.  
- Educational modules to support researchers and volunteers and help them be successful in their respective roles |
| **Returning Value Approach** | - Builds capacity and increases scientific literacy through training modules  
- Offers multiple avenues for volunteering (e.g., starting a project, contributing to a project, providing feedback on protocols, serving as discussion board moderator)  
- Provides equalizing opportunities for non-traditional researchers to directly govern, lead, partner in, and/or contribute to research  
- Builds community and social support by providing mechanisms for researchers and volunteers to directly engage with each other over shared interests |
| **Sources** | 1. *Citizen science frontiers: Efficiency, engagement, and serendipitous discovery with human-machine systems*  
2. *Welcome to the Zooniverse: People-powered research* |
Digital Strategies for Returning Value to Research Participants

Endnotes


