

Strength In Numbers Hackathon: Using a novel technology-focused brainstorming activity to engage stakeholders in intervention development.

Lisa Hynes
Department of Psychology,
West Virginia University,
USA

Mary Clare O'Hara
Endocrinology and Diabetes
Centre, Galway University
Hospitals & School of
Medicine, National
University of Ireland,
Galway, Ireland

Vincent Jordan
Office of the Chief
Information Officer, Health
Services Executive, Ireland

O. Clyde Hutchinson
Office of the Chief
Information Officer, Health
Services Executive, Ireland

Fergus O'Dea
NDRC, Dublin, Ireland

Molly Byrne
School of Psychology,
National University of
Ireland, Galway, Galway,
Ireland

Sean F. Dinneen
Endocrinology and Diabetes
Centre, Galway University
Hospitals & School of
Medicine, National
University of Ireland,
Galway, Ireland

Young adulthood has been identified as a particularly challenging time to live with and manage a chronic condition, like type 1 Diabetes (McKnight, Wild, Lamb, Cooper, Jones, Davis et al., 2015; Wiebe, Helgeson, & Berg, 2016). A growing body of research shows that living with type 1 Diabetes as a young adult is associated with more Diabetes-related problems as well as reduced wellbeing (Bryden, Dunger, Mayou, Peveler & Neil, 2003; National Health Service, 2015). Despite growing awareness of the risks faced by young adults with type 1 Diabetes, there is a lack of evidence-based guidance in the research for supporting young adults to improve self-management and outcomes (O'Hara, Hynes, O'Donnell, Nery, Byrne, Heller & Dinneen, 2016).

Addressing the needs of young adults: The D1 now study

The findings of an audit of the Young Adult Diabetes Clinic conducted in Galway University Hospitals confirmed poor outcomes similar to reports from other parts of the world and demonstrated the need to engage differently with this population (Casey, O'Hara, Cunningham, Wall, Geoghegan, Hynes et al., 2014). The research team was awarded a Health Research Award by the Health Research Board (HRB) in Ireland to establish an evidence base for developing a new intervention for young adults living with type 1 Diabetes, the D1 now study.

Based on the development phase of the Medical Research Council Framework for developing and evaluating complex interventions (Craig, Dieppe, MacIntyre, Michie, Nazareth, & Petticrew, 2008), four work packages were completed. To identify the evidence base related to improving outcomes among young adults with type 1 Diabetes, a systematic review of all interventions aimed at improving clinical, behavioural and psychosocial outcomes for young adults with type 1 Diabetes was completed (O'Hara et al., 2016). A qualitative study was conducted involving interviews with parents of young adults with type 1 Diabetes and diabetes service providers, and focus groups with young adults to develop a theoretical understanding of the drivers of young adult self-management (Hynes, O'Hara, Casey, Murphy, Byrne, & Dinneen, In prep). Utilising a methodology from behavioural economics, young adults' preferences

for characteristics of Diabetes clinics, and the delivery of education and support services, were assessed using a Discrete Choice Experiment. The final work package was to establish and integrate a Young Adult Panel (YAP) of Diabetes service users. Jigsaw Galway is a local youth mental health organization with an extensive track record of meaningful engagement with the young adults using their services. With the support of Jigsaw Galway, an eight-member Public and Patient Involvement (PPI) panel of 18 to 25 year olds living with type 1 Diabetes was recruited. The YAP have made significant contributions to all aspects of the research including development of research materials and dissemination.

Engaging stakeholders in intervention development

Recommendations for designing behaviour change interventions emphasize the importance of the development phase and collaboration with experts, particularly relevant stakeholders, to translate the evidence-base into a potentially effective intervention (Craig et al., 2008; Mc Sharry, Fredrix, Hynes, & Byrne, 2016). A consensus event, called the Strength In Numbers symposium was organized with the support of a Knowledge Exchange and Dissemination Scheme Award from the HRB, to gain stakeholder input into the D1 now intervention development process. The main conclusions drawn from the systematic review, qualitative research, discrete choice experiment and YAP engagement was that a new approach to working with young adults was needed and that this approach would need to be innovative, prioritise self-management support, harness the power of digital technology and social media, and engage young adults throughout the process.

The symposium took place over three days and

involved over 110 delegates, 10% of whom were individuals living with type 1 Diabetes. Delegates also included Diabetes service providers, technology experts, policy-makers and researchers. The symposium included three main activities; a Core Outcome Set Consensus meeting (funded by a New Foundations Award from the Irish Research Council) to identify outcomes which should be included in all future young adult type 1 Diabetes research, a conference, and an expert panel meeting. The expert panel meeting involved two parallel meetings, one focusing on reaching consensus regarding strategies for improving young adult self-management, and the other on identifying technology solutions to fit within an intervention, through a brainstorming activity called a Hackathon.

The Strength In Numbers Hackathon

A Hackathon is a dynamic, collaborative approach often used in the development of start-up technology businesses that brings together a diverse group of people with the relevant skills to create an output. Their use in healthcare innovation is increasing (Silver, Binder, Zubcevik, & Zafonte, 2016). Hackathons capitalize on the fact that many healthcare innovations are borne out of individual experience, for example a doctor trying to solve a problem. Supported by experts from the Irish Health Services Executive Office of the Chief Information Officer, and from the NDRC, the D1 now team chose to use the Hackathon format as a rapid and engaging approach to translating findings from the developmental phase of the research into feasible and innovative technology solutions. Harnessing digital technology to support self-management is widely regarded as an important approach and one that is particularly relevant for young adults (Yardley, Choudhury,

Patrick, & Michie, 2016; Monaghan, Helgeson, & Wiebe, 2015).

Hackathons are based on ideas developed in response to a clear problem statement with input from a diverse team. The planning and implementation of the Strength In Numbers Hackathon was guided by the Health Hackathon Handbook (MIT Hacking Medicine, 2016). The Strength in numbers Hackathon involved 28 participants, including representatives from Irish and multinational technology companies, local and national hospitals and universities, and eight young adults with type 1 Diabetes. Hackathon participants were provided with a summary of the findings of the D1 now study and a description of three modifiable focus areas identified based on the research findings, two weeks in advance of the Hackathon, to facilitate the development of their ideas. The three focus areas were: 1. The way young adults are introduced to the adult Diabetes clinic, 2. Attendance at Diabetes clinic appointments and contact between appointments, and 3. Building



Strength In Numbers Conference delegates

relationships between young adults and service providers.

The Hackathon participants attended the Strength In Numbers conference on day two of the symposium to gain a deeper understanding of young adult type 1 Diabetes self-management and engage in discussions with other delegates. The Hackathon began on day two of the symposium

immediately after the conference. The first part was a brainstorming session to generate ideas from the participants and started with young adults living with Diabetes describing opportunity and problem areas. As ideas were shared the IT experts suggested where technology may form part of the solutions to address those areas. The next phase was an open discussion on the ideas and potential solutions to converge on four or five ideas, with participants self-selecting into working teams based on having a minimum of one of each key stakeholder: a young person with Diabetes, a



D1 now Young Adult Panel members

Diabetes health practitioner, a health psychologist, and a technologist.

The following day teams began work on their proposals early with mini-milestones set to ensure teams clarified their target users, related their proposal back to the behaviour change evidence base, and they tracked towards a well-developed pitch.



Group work discussing intervention strategies during the Strength In Numbers Expert Panel meeting

Table 1*Hackathon proposal descriptions*

Hackathon Team Name	Proposal description
Transition App	<p>Platform & aim: Mobile app aimed at aiding timely transition from paediatrics to adult diabetes services.</p> <p>Setting: Paediatric diabetes clinic, school and social contexts, such as sports clubs.</p> <p>End-users: Parent and/or young person with type 1 diabetes</p> <p>Features: App is accessed through diabetes clinic WiFi. The app aims to enhance relationships between young people and their service providers, allow young people to access high quality educational content on the go, provide motivational advice from influencers and deliver rewards via gamification to encourage better self-management.</p> <p>Implementation: The reach of the app to its target population will be maximised using social marketing expertise.</p>
Injection, Pumps, Understanding and Management (IPSUM)	<p>Platform & aim: Mobile app and web portal for enhancing communication between young adults and service providers.</p> <p>Setting: Daily self-management</p> <p>End-user: Young adults with type 1 diabetes and service provider</p> <p>Features: App helps young adults log and monitor their carbohydrates, exercise, alcohol and blood glucose levels. Includes an in-built calculator to help determine insulin dose adjustments. Data will be visualised on a web portal to assist with clinic consultations and used to monitor trends to help reach collaborative goals between young adults and service providers.</p> <p>Implementation: App will be integrated with other smart devices (such as accelerometers and other wearables) to minimise manual input requirements from the young adults.</p>
SnapD1	<p>Platform & aim: Channel on the popular social media app called Snapchat, which sends young adults personalized motivating and informative content</p> <p>Setting: Daily self-management</p> <p>End-users: Young adults with type 1 diabetes</p> <p>Features: App integrates personalized motivational and educational content with a social network of peers with type 1 diabetes. App can send reminders, facts and top tips as well as providing young adult generated content and motivational pictures and comments.</p>
DiaLog	<p>Platform & aim: Website or mobile app to improve communication between young adults and service providers, and empower young adults as they transition to adult diabetes services.</p> <p>Setting: Paediatric diabetes clinic</p> <p>End-user: Young adults with type 1 diabetes and service providers</p> <p>Features: App allows young adults to find out about service providers present at each clinic visit and provides a platform for a 2-way communication between the diabetes clinic team and young adults. Young adults would complete a pre-consultation checklist asking how they are feeling and some questions they would like to discuss during visit.</p> <p>Implementation: App is activated when the hospital WiFi is accessed and includes a range of features for making the most of clinic visits by tailoring to individuals.</p>



Core Outcomes Set Consensus meeting

in table 1. Mobile applications, some with accompanying websites, were the most popular platforms. Of the four proposals, only one involved the use of an existing platform, Snapchat, to create a social network of young adults with type 1 Diabetes. Transition from paediatric to adult Diabetes clinics was the focus of one of the applications proposed, while communication with service providers was the focus of the other two applications.

Each Hackathon team pitched their idea to the expert panel, who then chose the winner of the Best Pitch Award. Pitch development and delivery, and lively competition are key characteristics of Hackathons. The team who developed the proposal for SnapD1 were voted the winning team, and included a Diabetes Nurse Specialist, PhD student in health psychology, a young adult living with type 1 Diabetes, an IT consultant, and a start-up developer/biomedical engineer.

The Strength In Numbers Hackathon experience and future directions

The Strength In Numbers Hackathon, and symposium as a whole, was a rewarding and

enlightening experience and facilitated the D1 now research team to produce a proposal for a complex intervention to improve self-management among young adults with type 1 Diabetes. In the next phase of the study the proposed intervention will be further refined, before beginning a pilot randomised feasibility study.

A growing body of research demonstrates the need to change the way diabetes services are delivered to young adults with type 1 Diabetes, as well as other chronic conditions such as asthma and Cystic Fibrosis (O'Hara et al., 2016; Okumura, Ong, Dawson, Nielson, Lewis, Richards, Brindis et al., 2014). Health psychology has much to contribute to facilitating the use of novel approaches such as Hackathon to translate evidence into intervention components. Iterative processes of development, engagement with stakeholders, testing and adaptation are recommended to develop effective mHealth interventions, which contribute to the evidence base as well as achieve positive outcomes (Yardley, Spring, Riper, Morrison, Crane, Curtis, Merchant et al., 2016). Through continued engagement and collaboration with the stakeholder network created through the Strength In Numbers Hackathon, the D1 now study aims to enhance engagement between young adults and service providers, to improve self-management and to ultimately impact on diabetes and psychosocial outcomes of young adults living with type 1 Diabetes.

Acknowledgements

The D1 now study team and Hackathon collaborators would like to thank the Strength In Numbers Hackathon participants for their outstanding commitment to the event and continued engagement with the research.

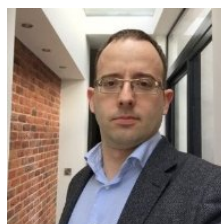
Statement of competing interests

None

References

- Bryden, K.S., Dunger, D.B., Mayou, R.A., Peveler, R.C., & Neil, H.A.W. (2003). Poor prognosis of young adults with type 1 diabetes: a longitudinal study. *Diabetes Care*, 26, 1052-1057. doi: <http://dx.doi.org/10.2337/diacare.26.4.1052>.
- Casey, R., O'Hara, M.C., Cunningham, A., Wall, D., Geoghegan, R., Hynes, L., McGuire, B., Gately, M., Bell, M., and Dinneen, S.F. (2014). Young adult type 1 diabetes care in the West of Ireland: an audit of hospital practice. *Quarterly Journal of Medicine*, 107(11), 903-908; doi: 10.1093/qjmed/hcu103.
- Craig, P., Dieppe, P., MacIntyre, S., Michie, S., Nazareth, I., Petticrew, M. (2008). Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*, 337, 979-983.
- Hynes L., Byrne M., Dinneen S.F., McGuire B.E., O'Donnell M., Mc Sharry J. (2014). Barriers and facilitators associated with attendance at hospital diabetes clinics among young adults (15-30years) with type 1 diabetes mellitus: a systematic review. *Pediatric Diabetes*, 1-10.
- O' Hara, M.C., Hynes, L., O'Donnell, M., Nery, N., Byrne, M., Heller, S.R., & Dinneen, S.F.(2016). A systematic review of interventions to improve outcomes for young adults with type 1 diabetes: Towards the development of a new intervention. *Diabetic Medicine*. doi: 10.1111/dme.13276
- Hynes, L., O'Hara, M.C., Casey, D., Murphy, K., Dinneen, S.F., & Byrne, M. (In prep). A theory-based qualitative approach to the development of an intervention to improve outcomes among young adults with type 1 diabetes.
- Mc Knight, J.A., Wild, S.H., Lamb, M.J., Cooper, M.N., Jones, T.W., Davis, E.A. et al. (2015). Glycaemic control of Type 1 Diabetes in clinical practice in the 21st century: an international comparison. *Diabetic Medicine*, 32, 1036-1050.
- Mc Sharry, J., Fredrix, M., Hynes, L., & Byrne, M. (2016). Prioritising target behaviours for research in diabetes: using the nominal group technique to achieve consensus from key stakeholders. *Research Involvement and Engagement*, 2 (14). doi: 10.1186/s40900-016-0028-9.
- MIT Hacking Medicine. (2016). Health Hackathon Handbook. Retrieved from http://hackingmedicine.mit.edu/assets/Health_Hackathon_Handbook.pdf.
- Monaghan, M., Helgeson, V., & Wiebe, D. (2015). Type 1 diabetes in young adulthood. *Current Diabetes Reviews*, 11(4), 239-250.
- National Health Service (NHS). (2015). National Diabetes Audit 2012-2013. Report 2: complications and mortality. Leeds: Health and Social Care Information Centre.
- Okumura, M.J., Ong, T., Dawson, D., Nielson, D., Lewis, N., Richards, M., Brindis, C.D., & Kleinhenz, M.E. (2014). Improving transition from pediatric to adult cystic fibrosis care: programme, implementation and evaluation. *BMJ Quality and Safety*, 23, i64-i72. doi: 10.1136/bmjqs-2013-002364.
- Silver, J.K., Binder, D.S., Zubcevik, N., & Zafonte, R.D. (2016). Healthcare hackathons provide educational and innovation opportunities: A case study and best practice recommendations. *Journal of Medical Systems*, 40(7), 177. doi: 10.1007/s10916-016-0532-3.
- Wiebe, D.J., Helgeson, V., & Berg, C.A. (2016). The social context of managing diabetes across the life span. *American Psychologist*, 71(7), 526-538. DOI: <http://dx.doi.org/10.1037/a0040355>.
- Yardley, L., Choudhury, T., Patrick, K., & Michie, S. (2016). Current issues and future directions for research into digital behavior change interventions. *American Journal of Preventive Medicine*, 51(5), 814-815. doi: <http://dx.doi.org/10.1016/j.amepre.2016.07.019>

Yardley, L., Spring, B.J., Riper, H., Morrison, L.G., Crane, D.H., Curtis, K., Merchant, G.C. et al. (2016). Understanding and promoting effective engagement with digital behavior change interventions. *American Journal of Preventive Medicine*, 51(5), 833-842. doi: <http://dx.doi.org/10.1016/j.amepre.2016.06.015>.



Fergus O'Dea
NDRC, Dublin, Ireland
fergus.odea@ndrc.ie



Dr Lisa Hynes
Department of Psychology, West Virginia University, USA
lisa.hynes@mail.wvu.edu



Dr Molly Byrne
School of Psychology, National University of Ireland, Galway, Galway, Ireland
molly.byrne@nuigalway.ie



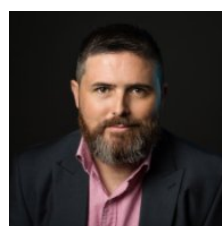
Mary Clare O'Hara
Endocrinology and Diabetes Centre, Galway University Hospitals & School of Medicine, National University of Ireland, Galway, Ireland
maryclare.ohara@hse.ie



Prof. Sean F. Dinneen
Endocrinology and Diabetes Centre, Galway University Hospitals & School of Medicine, National University of Ireland, Galway, Ireland
sean.dinneen@nuigalway.ie



Vincent Jordan
Office of the Chief Information Officer, Health Services Executive, Ireland
vincent.jordan@hse.ie



O. Clyde Hutchinson
Office of the Chief Information Officer, Health Services Executive, Ireland
clyde.hutchinson@hse.ie