

NIHR Devices for Dignity Medtech Co-operative (D4D)

Living Well for Longer

Patient Carer and Public Involvement and Engagement Strategy

1. Introduction

Devices for Dignity (D4D) are an organisation founded by the National Institute of Health Research (NIHR). We are proud to be hosted within the NHS and we work to develop and deliver usable technologies for - and in partnership with, people with long term and multiple health problems and their carers, empowering them to live well for longer; improving and maintaining independence and enabling better health outcomes and quality of life.

We aim to build on and implement health research and innovation across our 3 clinical themes; Long Term Neurology, Diabetes and Renal, linking with our local and national networks in order to expedite adoption of new technologies in order to bring benefit to patients and their families.

2. D4D's vision for Patient, Carer and Public Involvement and Engagement (PPIE)

We aim to work in inclusive and respectful collaboration with patients, carers and the public to deliver health technologies that are fit for purpose, having been shaped by- and with those people who need them.

Work to better understand the health challenges of people with long term and multiple conditions is fundamental to our approach to identifying priorities for research and building collaborative project teams in order to develop innovative technology to meet these needs.

Our approach is based on optimising meaningful and impactful participation, involvement, and engagement of patients and their families, carers and the public. This collaboration principle (co-production) is to be included throughout the development, evaluation and adoption stages of each project.

3. Strategic priorities

D4D's partnership working with patients and the public has been embedded in our programme's operation and delivery since its inception and we remain committed to continuous improvement via links with partnership organisations, reflections on National Standards for PPIE in Research and by seeking feedback from our PPIE partners.

In order to help us achieve our vision, we have five strategic priorities, which have been developed with reference to our D4D Five Year Plan, across our Theme areas, the NIHR INVOLVE National Standards Guidelines, and to key findings from the D4D National Patient Led Event in 2015, which were reported in [My Dignity Means: Patient Voices](#).

Throughout this document, we use the NIHR INVOLVE definitions of Involvement, Engagement and Participation. By Patients and Public, we refer to:

- Patients in specific condition groups (and/or multiple conditions)
- Family/friends/unpaid carers
- General public
- Expert patient consultants
- Patient organisations and charities

Strategic Priority 1: Provide inclusive opportunities for dialogue and for partnership working

We want to expand and deepen our thriving PPIE networks to initiate meaningful dialogues that will inform the prioritisation, design and delivery of our research and innovation programme.

We aim for this engagement to be fulfilled at board level, in order to influence the strategic development of D4D, at core team level via our PPIE Co-leads and Theme Leads via theme specific patient advisory groups, and throughout each project via project specific groups and our broader PPIE networks.

We will use plain language and supportive communication strategies where these are required and also link in with other PPIE groups and organisations to maximise reach and efficiencies for information and best practice sharing, and to avoid duplication.

We aim to offer a range of roles for participation – from board meetings and membership of project groups through to occasional participation via questionnaires or social media to ensure a diverse and flexible methodology for representative and meaningful collaborations. We will be clear about expectations of these roles in order to achieve a shared understanding of what might be involved.

We are working with Salford University to explore how we can use digital/social media as tools to broaden our patient engagement and will also continue to hold specific project face-to-face groups and sandpit events. Learning from this and from other innovative uses of social media will be transferred to other projects within the D4D portfolio. We will also enable continuous feedback so as to achieve continuous refinement of our projects and processes.

(Links with NIHR INVOLVE PPIE Quality Standard 1: Inclusive Opportunities, Quality Standard 2: Working Together and Quality Standard 4: Communications).

Strategic priority 2: Illustrate the evidence of impact of the patient, carer and public voices and of partnership working

Part of the learning from the 2015 Patient Led Event was that our PPIE partners would like greater feedback from the different organisations they work with on the impact that their input has had. They advised us to “Go where the patients go” with news.

We currently feedback on project progress and outcomes via annual reports to NIHR, face to face meetings with project specific expert patient groups and networks, via our monthly newsletters, and via videos – both on our website and YouTube. We are also communicating via Twitter and other social media networks. We share exemplars of successful partnership working with other partnership organisations and in publications, in order to demonstrate impact from our PPIE and to learn from exemplars from other groups. Where appropriate, we also welcome PPIE partners as co-authors on research publications and conference presentations.

Without PPIE, addressing effective usability for new technologies is not possible. An important example of impact is making technologies safer and easier to use through effective patient involvement throughout design and development. This is a regulatory requirement of the current medical device directive as supported through standards such as EN 62366 and IEC/EN 62304. In the UK, the Medicines and Healthcare products Regulatory Agency (MHRA) recognised its importance by publishing ‘Human Factors and Usability Engineering – Guidance for Medical Devices Including Drug-device Combination Products’ in

2017. This aspect is an example of how the Medtech, Human Factors and clinical themes will integrate with PPIE.

We will consult with our PPIE partners on ways to evaluate and further improve these feedback mechanisms.

(Links with NIHR INVOLVE Quality Standard 4: Communications and Quality Standard 5: Impact)

Strategic priority 3: Continuous improvement through shared learning

We will identify where patients, carers and public may wish to participate in training and mentoring activities in order to clarify the range of participation roles and opportunities available to them and to support and enable them in fulfilling these roles.

We will link with PPIE best practice evidence and initiatives in order to deepen our own learning and will systematically undertake evaluations of user experience of PPIE working, sharing learning locally and nationally.

We are keen to evaluate the quality and impact of our PPIE working. D4D is a registered NIHR INVOLVE “Freestyle site”, evaluating the NIHR INVOLVE Quality Standards for PPIE in Research. We are also working in partnership with KPIN (a network of Kidney Patients, Charities, Academics and Clinical organisations) and our host organisation, Sheffield Teaching Hospitals NHS Trust, who are two of the 10 INVOLVE Quality Standard test bed sites to help us achieve our aim to develop a metric for capturing and evaluating the quality of our PPIE development.

(Links with NIHR INVOLVE Quality Standard 1: Inclusive Opportunities and Quality Standard 3: Support and Learning)

Strategic priority 4: Collaboration with key partners

We will continue to develop effective partnerships with individuals, patient/public groups, regulatory bodies, industry, charities, health and social care service providers and academia in order to co-develop research priorities, and to co-develop and delivery of projects.

These partnerships will also be explored in order to identify gaps in research and innovation. We will continue to work closely with (among others):

- NIHR INVOLVE
- The Sheffield Teaching Hospitals Clinical Research and Innovation Office (CRIO) PPI Panels
- The UK Clinical Research Facility (UKCRF) networks
- The Technology and Innovation Transforming Child Health (TITCH) network and NIHR CYP-MEDTECH Children and Young People’s Medtech Co-operative
- The Academic Health Science Networks (AHSN)
- Applied Research Collaboration (ARC)

We look to further develop our relationships with:

- The National Innovation Centre for Aging
- The NIHR Innovation Observatory
- VOICE Global
- Healthwatch
- Condition specific patient organisations and charities

(Links with NIHR INVOLVE Quality Standard 1: Inclusive Opportunities and Quality Standard 5: Impact)

Strategic priority 5: Governance

D4D has PPIE advocacy at a strategic level from three PPIE representatives on the D4D Steering committee who will oversee this work; Professor Ade Adebajo (DoH Lead for Equality and Diversity and NIHR INVOLVE Associate), Alan Norton (CEO Into Independence Ltd.) and Professor Wendy Baird (Partnership Director NIHR INVOLVE RDS).

Within the Core team we have 2 PPIE Co-Leads; David Coyle (Expert patient representative) and Lise Sproson (Senior Research Associate, D4D) who provide leadership and co-ordinate and develop the PPIE networks. David and Lise oversee PPIE strategy development and implementation, and are the main contact points for collaboration with other organisations and networks. They are also responsible for co-ordinating development of funding bids for PPIE work and the evaluation of the quality and impact of PPIE within and across projects, working closely with Nathaniel Mills for the D4D paediatric projects.

A summary of D4D PPIE activities and impact will be included in D4D annual reports to NIHR. We will also report to NIHR INVOLVE regarding our participation in the Quality Standard test beds project.

(Links with NIHR INVOLVE Quality Standard 6: Governance)

These strategic aims will be delivered and evaluated according to a detailed Implementation Plan that is reviewed on a regular basis within our team.

Devices for Dignity would like to acknowledge the valuable contributions and feedback received from: Ade Adebajo, David and Lesley Statham and Alan Norton in the preparation of this strategy

Lise Sproson and David Coyle December 2018

Due for review November 2019