

My Dignity Means: Patient Voices

A report on My Dignity Means: A Patient-Led
Event and the responses received in our
Independence and Dignity Survey

#MyDignityMeans

2 December 2015

Executive Summary

In June 2015 NIHR Devices for Dignity HTC (D4D) held our first Patient-led Event, the culmination of months of preparation and public, patient and carer engagement, and a national independence and dignity survey.

The event and associated public engagement activities highlighted several key issues:

- The need for services and devices to be designed to cater for people who live with multiple long-term conditions or disabilities, not just single isolated conditions or disabilities.
- Being able to manage the practical aspects of day-to-day living with long-term conditions and disabilities is important, but clinical effectiveness is not enough on its own; truly successful solutions need to be developed with reference to the full context of the person's life, including offering the person choice, dignity and independence.
- For patients, awareness of and access to new technology solutions is important. There is currently no single system through which the public can reliably find new technologies or user reviews of devices.

This report summarises our findings, and demonstrates where and how we are using the opinions and information provided by patients, carers and the public to influence our work, and health services in general.

"Day-to-day living would be better if...."

Researchers, architects, product designers etc. should involve people with the condition in the planning and design process of the products and services that they produce for those people."

– *Anonymous feedback following the event*

Watch a short film about our event:

<https://www.youtube.com/watch?v=x6e0ST8opMw>

Introduction

Patient and Public Involvement (PPI) has always been an integral part of NIHR Devices for Dignity HTC's approach. We develop technology solutions to real clinical problems; the input of people living with long-term conditions and their carers is vital both in identifying these problems, and in developing solutions.

In 2014 we formed a Patient Advisory Team to work with us to develop a meaningful patient-led engagement event: Kate Allatt, a survivor of locked in syndrome, David Coyle, a renal patient and cancer survivor, and Roz Davies, who lives with Type I diabetes. Their view was that it would be valuable to find out from people with long-term conditions and their carers what they recognise as dignity and independence issues, and use this as a basis for our event. Consequently we launched our Independence and Dignity Survey. We used the responses to help plan the programme for My Dignity Means: A Patient-led Event, which took place in June 2015.

The purpose of the survey and event was to give people the opportunity to tell us what is important to them, and to influence our activities over the coming years. This report summarises the survey responses and the discussions that took place at the event, and provides an update of how we are working to ensure we're addressing the issues that people with long-term conditions and their carers care about.

Survey development

We wanted to give people and their carers the chance to tell us about the effects of their conditions on their everyday lives, to see whether there are any issues that D4D could address through the development of technology solutions.

It can be difficult to find people who are willing to talk in depth about very personal medical issues, and the impact this can have on their lives. It can also be difficult to ask questions that people are prepared to answer. Together with the Patient Advisory Team we devised some initial questions based on personal experiences of living with one or more long-term conditions. Kate trialled and refined these questions on social media with a variety of online discussion groups that she runs that have a large existing membership.

“...[Our intention was] to come up with an idea and event that actually put patients at the forefront ... and to actually understand their unmet needs from the horse’s mouth, and then to help design products that will assist them to become more independent. We went about getting patient opinion with the survey, a survey that identified all the areas that would affect people’s daily living activities so showering, going upstairs, paying the bills, opening medication. We broke down every element into subsections and formulated a survey.” – *Kate Allatt*

Using feedback from these preliminary conversations, and with further feedback from other patients, The Dignity Council, the British Kidney Patient Association (BKPA), and a market research professional, we developed and launched our Independence and Dignity Survey.

We would like to thank everyone who completed the survey, and all the individuals and charities that helped us to reach the wide range of individuals that completed our survey.

Due to the success of the survey we later re-opened it, though our analyses are based on the initial responses. The survey can be accessed online:

www.devicesfordignity.org.uk/ppc/nationalsurvey

Survey findings

We received 655 responses to our survey, many including detailed personal and medical information. We are grateful for every response we received, and have looked at each response individually and anonymously. Over 30 different long-term conditions are represented, with many responders reporting multiple conditions. Despite the range of conditions, we found that many people reported similar practical difficulties with activities of daily living (their “profile of need”), and similar issues with the devices they use to manage their conditions.

Publicly-funded and charitable organisations are welcome to contact us to discuss specific queries that the survey data may provide insight into.

Who responded to our survey?

- 79% of responses were received from people with long-term conditions or disabilities, with the remaining 21% of successfully completed responses received from carers, including people with both caring roles at home, and people with professional caring roles.
- 73% of responses were received from women, and 27% from men. A couple of responders chose not to reveal this information.
- 63% of responses represented working-age people, 18-64 years. Of this group, 28% reported being unable to work the hours they would like, and 40% reported being unable to work at all due to their condition.

Which activities of daily living were affected most frequently?

Percentage of people reporting difficulty	Activity that people report experiencing difficulty with
37%	Walking without assistance
40%	Bathing and showering
46%	Going up or down stairs
36%	Preparing own meals
52%	Doing housework

Which self-care activities did people report as difficult most frequently?

Percentage of people reporting difficulty	Activity that people report experiencing difficulty with
35%	Sleeping
34%	Continence
18%	Managing fluid restrictions
20%	Managing food restrictions
18%	Swallowing

Which aspects of managing their long-term condition did the greatest proportion of people report finding difficulty with?

Percentage of people reporting difficulty	Activity that people report experiencing difficulty with
25%	Monitoring their condition
26%	Doing the exercises suggested by a therapist
40%	Getting to the doctor's or hospital, and getting around once they're there
35%	Opening medication

Which aspects of communication did people most frequently struggle with?

Percentage of people reporting difficulty	Activity that people report experiencing difficulty with
18%	Reading
31%	Writing
15%	Hearing
25%	Speaking
17%	Using a phone
18%	Using a computer

Long-term condition management, devices and improvements

People who responded to the survey also had the opportunity to tell us what conditions they have/have had, devices they currently use, and what they'd change about them. Several recurrent messages became clear about managing conditions and using devices:

Getting the design right is important, but giving people the opportunity to choose or personalise their technologies to suit their cultural needs, age, gender, personal tastes and lifestyles is important too. An important factor driving people's need for choice is that many people live with more than one long-term condition or disability, despite health services often being configured to treat just one targeted condition; healthcare solutions need to reflect and respect this.

Worryingly, the improvements to their devices that many people described can already be found on other devices available elsewhere in the market place. In some cases this lack of access to the preferred product is due to availability and cost, and in some cases it was the result of the updated device not being well publicised.

Overall, the message was clear – it shouldn't be too much to ask that devices be designed with patients' broader needs in mind, not just their clinical needs. If a healthcare solution does not work within the full context of a patient's life, it is not a complete solution.



Expert Theme Analysis of Survey Responses

As NIHR Devices for Dignity HTC includes specific Expert Themes, we also reviewed the survey responses from those perspectives.

Urinary Continence Management

There were 195 responders who have experienced continence related problems.

Responders reporting continence issues identified continence pads/pants and catheters to be the most frequently used medical device for continence management. A significant proportion of the users also use other non-invasive devices such as condom catheters, urinals or commodes. Some participants also reported using non-medical devices such as empty milk bottles to collect urine.

The majority of problem with continence devices that were reported related to continence pads and catheters. Continence pads are often too bulky, uncomfortable and the users would like to improve the absorption and discreetness of their usage. Catheter users referred to reliability of taps, comfort of leg bag strapping and difficulty of using with arthritic hands.

A large number of unmet needs relate to the discretion of stoma bags. Users would like stoma bags that do not make “cracking” noises from plastic material, and that are less bulky. There were many suggestions related to changing the colour of the bags to make them look less medical. Several problems that were reported related to leaking of bags, or suggestions for alarms for when the bag is full. A number of users would also like to have flushable bags.

Assistive and Rehabilitative Technologies

Our Assistive and Rehabilitative Technologies theme seeks to develop technology solutions to help support people in living as independently as possible; this covers many aspects of everyday life, both

at home, and whilst in hospital. We asked what types of equipment and home adaptations people use, and divided our survey analysis into three groups in line with our areas of expertise:

- Communication (including speaking, thinking, vision/hearing, reading/writing, use of the telephone and communication aids) – 47% of people use a device to help them communicate
- Eating and Drinking (including food preparation, non-oral feeding devices, specialized diets and also teeth/mouth care) – 16% of people use a device to help with food/drink problems
- Mobility (including getting around inside and outside the home, hand dexterity and house adaptations and devices) - 55% use a device to help them get around or manage physical tasks.

Many of the people currently using devices have ideas about how these could be improved – the most popular suggestions were:

- Improved ease of use
- More acceptable design (e.g. age appropriate, more discreet, less noisy, more attractive)
- Reduced size/weight of the devices

We also learned from many people that it can be confusing to know which of the many currently available products might suit their individual needs. There is much information on the internet but this is not as useful as having the opportunity to try out products before buying...buying before trying can lead to expensive purchases that then remain unused. A popular idea was an easy to access product guide which included some kind of user rating system.

Renal Technologies

The Devices for Dignity Renal Technologies theme covers the full kidney failure life cycle from early detection of kidney disease and management of decline in kidney function, kidney failure and replacement with dialysis, to kidney transplant and life post-transplant. People requiring dialysis can be treated in hospital, or may opt to self-manage at home. People who dialyse at home receive additional training, and may become very knowledgeable in managing their treatment, and in the technologies that they use routinely.

People identified areas for which new product development is required, though solutions to some of the issues that people mentioned already exist. Many people also commented on their technologies to say that it's not just how well they work that is important, but also how portable they are and how they look, feel and sound. Issues relating to the amount of space needed for the dialysis machines and supplies were a common theme.

Broadly speaking the 41 survey responses from renal patients (both home- or hospital-based) and their carers showed several areas in which they differed from the survey findings for the whole 655 responses:

- Food and fluids – 51% of responders in this category reported issues with managing their food/dietary restrictions, which can be complex, and 37% reported issues with managing fluid intake restrictions.
- Mobility and physical activities – 41% reported difficulty with walking without assistance, and 61% reported difficulty in doing the housework.
- Transport (for patients dialysing in hospital)– 49% of responders reported difficulties with getting to/from hospital, and 39% cited difficulties in getting around the hospital once they were there.
- Self-management – 39% cited difficulty in monitoring their condition, with 46% reported finding it difficult to remember their medication.
- 54% of renal patients reported difficulty in managing pain.

A significant number of renal patients have more than one condition to manage. This was reflected in the survey responses: 19% reported diabetes, 24% reported lung problems, 19% reported cardiovascular problems, and 19% reported mental health problems. This highlights the need that many patient groups have for devices and services that respect the whole individual, rather than treat a single clinical aspect. One responder reported being supplied with crutches that were too heavy to use; they had a fistula to maintain.

Discussions at our event

At our event we asked attendees to join small discussion groups around NIHR Devices for Dignity HTC's existing Expert Themes, and build on the summarised survey responses to tell us what they thought priorities for future work in those areas should be:

Priorities identified around the Renal Technologies theme:

1. Use phone and wrist band technology as the basis for a new generation of mobile monitoring devices that can monitor personal levels of hydration, potassium and phosphate, and alert the wearer if they're under/over hydrated, potentially using a traffic light system to provide early warnings.
2. Truly transportable dialysis and peritoneal dialysis machines.
3. Home dialysis machines that are fit for purpose in the home, taking up a small space footprint in the home, offering a significant reduction in the amount of consumables used and that need storing, and with no noise or light emission during nocturnal dialysis.
4. Greater access to holiday dialysis and temporary self-care options.
5. Match the introduction of new technologies in hospital-based haemodialysis and peritoneal dialysis machines with the introduction of equivalent home-based machines.
6. Improvements to transport for renal patients, including greater wheelchair accessibility.
7. Practical education material that is easy to access.
8. Education and awareness of the importance of fistula safety, such as the importance of not needling an arm with a fistula, the adverse effects of dehydration, and protection of the fistula when undertaking physical activity.
9. Better psychological support for patient and families, including patient experience and depression monitoring tools.
10. Easier access to information on benefits and forms of care support.
11. Solutions to pain around the drain site for peritoneal dialysis patients.
12. Who do you call when you have a problem? A simple and clear contact list, perhaps embedded in a phone app.
13. Infection monitoring to detect infection earlier, allowing earlier treatment, and potentially reducing hospital admissions
14. Reminders for medicines – prompts for when and what to take, and a way of tracking what has already been taken.
15. Greater customisation in the way services and devices work, taking into account different perceptions and needs of younger and older patients and carers, i.e. one size does not fit all.
16. Services that fit around the lives of patients more readily.
17. Ways to manage care that takes account of the other conditions that each individual lives with.
18. Better information on 'what to expect' for those who have been recently diagnosed – provided at the right time and in the most suitable format to fit each patient's needs.
19. An information website where patients or carers can search for devices or services under development that are looking for patient involvement, and that also describes different ways in which patients and carers can get involved.

Priorities identified around the Urinary Continence Management Theme:

1. More effective communication between healthcare professionals and patients, and between services.
2. Provision of more relevant information at diagnosis.
3. Personalised care plans that take into account other conditions that the person may have, and give people the opportunity to try different options (catheter at night; pads during the day).
4. Education around recognising and eliminating triggers, fluid management, and the fluid content of food.
5. A wider range of pads and no 'postcode lottery' for access to pads on prescription.
6. More sympathetic treatment of the condition by the media, especially around male incontinence.
7. An easy to use bladder diary to assist record keeping and diagnosis.
8. Psychological support for people with incontinence, and carers.
9. Improved availability and ease of access to public toilets.
10. Easy ways to remove garments for those who have urgency.
11. Improved awareness of the symptoms of incontinence and urinary tract infections to enable effective self-management by people who wish to use wearable, non-invasive technologies such as pads.
12. Catheters – discrete and comfortable, not cumbersome and painful.
13. Interventions (e.g. valves) that can be used easily by people with dexterity challenges.
14. An app to help people locate the nearest appropriate toilet.
15. Apps to remind people when to go to the toilet, or to help them re-train their bladder during rehabilitation.
16. Greater access to treatments such as sacral neuromodulation and botox.
17. Earlier diagnosis of infections.
18. More effective diagnosis and management in primary care (GPs) that takes into account lifestyle/behavioural changes, as well as medication or referral.
19. Training and support for healthcare professionals to enable better recognition, management and treatment of patients.

Priorities identified around the Assistive and Rehabilitative Technologies Theme:

Communication

1. Communication aids that can use pictures rather than words.
2. Communicating. The 'worst thing' is that "people make assumptions about intellect " – attendees felt that there is a need for making the public aware that they should not assume that people who use communication aids cannot understand what is being said to them
3. Access to communication aids for children and help with funding – speed up the process of access. Attendees told us that there is currently too much variation in the process for securing funding for communication aids – this makes the process lengthy and confusing.

Eating and drinking

4. Portion size management – size of ‘particles’. Attendees requested development of devices such as size guides to aid cutting food consistently into safe and manageable mouthful sizes.
5. Technology that changes fluid consistency to aid swallowing and reduce ‘tickle’ factor
6. Technology to help people with swallowing problems so that they can clean their mouth and teeth without the risk of choking on toothpaste or water
7. More help with eating/drinking in hospital

Mobility

8. Physiotherapy/rehabilitation options built into wheelchair design.
9. A way to transfer from a wheelchair to dentist’s chair comfortably and easily.
10. Better options for upper limb rehabilitation.
11. Better wheelchair design – to facilitate greater comfort and ease of daily activities while in the chair (e.g. a retractable knee support).
12. Portable ramp for wheelchairs for small obstacles/kerbs.
13. Improved technology to enable control of devices within the home – for example control of lights, television, security systems etc. Some people have limited energy, and find it valuable to conserve their energy for other activities.
14. Lobbying - attendees saw value in having collective access to people who can influence policy, such as the Disability Minister.
15. Design buildings with better accessibility including space to turn wheelchairs in lifts and powered internal doors.
16. Websites similar to Amazon or Trip Advisor to provide a forum for review and rating by those who have used the products, and where people who use assistive technologies can go to explore the range of products that are currently available. This may help the “buy before you try” challenge that many attendees told us can lead to expensive purchases for items which turn out not to suit their particular needs.
17. Aesthetically appealing wearable robotics and devices.

Comments around health services in general received from all theme discussions included:

Services should be more joined up – there should be better communications between clinicians, especially for those with multiple long-term conditions, and between different care providers. It was also noted that earlier, greater involvement and engagement of patients would be valuable to projects, and that this should be tackled through both traditional and social media. In an ideal world there would also be better communication between patients and industry.

There is tremendous potential for Businesses and the NHS to identify and invest in technological solutions that can be applied across multiple disciplines rather than each discipline designing a slightly different version of the same core solution.

Patient-led events, like this one, which can draw together experts from different areas of medicine, are a great platform for sharing ideas and facilitating outcomes that can be applied across medical disciplines.

One discussion group proposed a model that would enable device developers to access the expertise of the NHS; the model described was very similar to D4D's existing process.

What happened next?

In the six months that have elapsed since our event and survey analysis, we have worked on a range of activities as a result of what people have told us, including building new relationships, ways to facilitate public involvement, and taking projects forwards.

Activities we're undertaking in response to specific survey and event comments:

- We are collaborating with a range of partners to develop a website to enable peer reviews of devices.
- We are assessing all survey responses to determine where new unmet clinical needs have been identified, and will take these forwards with industry partners where appropriate.
- 35% of responders cited issues with sleeping. As a consequence we have established contact with some sleep experts to further explore the key issues. We are also seeking further perspectives directly from patients, and are actively supporting the development and trialling of a sleep innovation.
- Stoma care was mentioned repeatedly in the survey. We are in discussion with the other Healthcare Technology Co-operatives and two industry partners for further exploration.
- Priorities that were identified included an electronic bladder diary and better treatment of urinary tract symptoms in primary care – we are establishing a multi-organisational team and have applied for funding to explore whether lower urinary tract symptoms in men can be better assessed, managed and treated.
- Some people would like flushable materials to be available to help them better manage their urinary continence issues. We are exploring collaborative opportunities to develop novel materials for this purpose.
- We are discussing urinary tract infection diagnosis with experts across primary and secondary care with a view to improving patient experiences and diagnosis.

Relationships that we are building as a direct result of the event and survey:

- We are establishing closer links with Parkinson's UK, with a view to beginning some collaborative projects around urinary continence management.
- We will work with charitable and publicly-funded organisations that approach us with specific questions that the survey data may address.

Activities to facilitate greater public involvement:

- We have provided guidance to other NIHR infrastructure organisations in facilitating patient input into projects and organising patient-led events.
- We are revising our approach to Public and Patient Involvement (PPI) in our projects. We already have a well-established PPI process, but will make further improvements based upon feedback received at the event – participants will receive feedback from projects for longer after their involvement has ceased, and more information on what they're likely to be committing to from the start of projects.

- We will use social media to reach a wider range of people to seek opinions around projects from start up.
- We would like to contact event attendees for opinions on our projects, and to invite people to become actively involved in relevant projects.
- We will approach event attendees to ask for further opinions on the priority areas identified.
- Our experience and feedback from the Patient-led Event has helped us to identify small practical changes that we could make to future events that would make involvement easier for attendees with certain conditions.

Thank you to all the survey responders and attendees at our event, your opinions have been very valuable. If you would like to comment further upon any aspect of this report, please contact us at enquiries@devicesfordignity.org.uk.

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We Love Life

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