NIHR | Devices for Dignity MedTech Co-operative

Long Term Neurological Conditions Unmet Needs Workshop

1st February 2019

Unmet Needs Identification and Idea Generation Report

On Friday 1st February 2019, the NIHR Devices for Dignity Med Tech Cooperative (D4D) in partnership with the Yorkshire & Humber Academic Health Science Network (AHSN), hosted a collaborative workshop to identify unmet needs for people living with long term neurological conditions and create project teams to develop solutions to address those needs.

Attendees at the event, included people living with or caring for people with long term neurological conditions, researchers, health care professionals, designers, and commissioners, who shared experiences, knowledge and expertise within the themes of:

- Sleep;
- Arm Function;
- Balance & Mobility;
- Monitoring;
- Environment
- and Remote Support.

Attendees were invited to choose one of the themes to focus on during the day's activities and to be prepared to work in small collaborative and creative groups. Themes were selected based on information provided at registration, insights from the James Lind Alliance and Devices for Dignity previous research.

The themes were cross-cutting across a range of conditions, diseases, ages so attendees were invited to think creatively around them and come to the session with their own ideas for themes if they felt something important was not being represented.

This report summarises the:

- unmet needs identified within the themed groups (figure 1),
- the range of ideas generated,
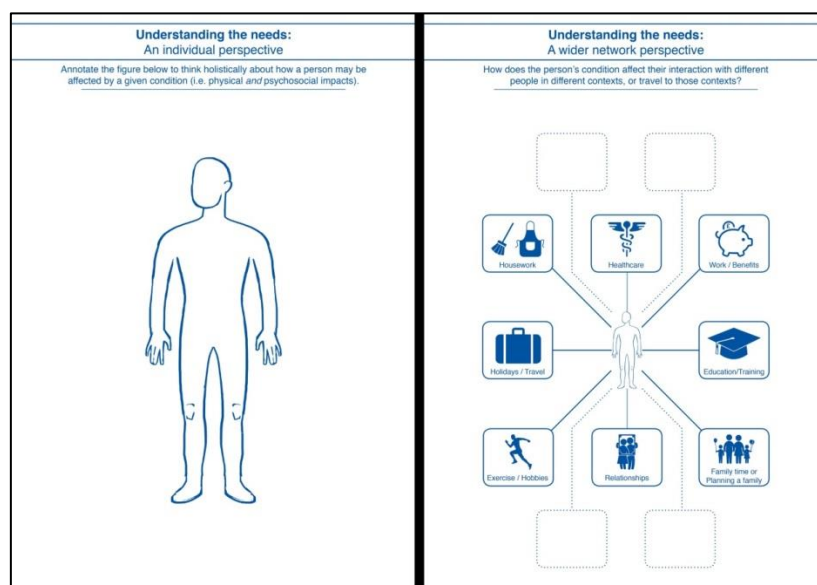- the priority ideas selected within each group,
- workshop feedback.

Figure 1: Understanding the needs

Sleep Theme

Unmet Needs & Challenges Identified

- Safety issues associated with wandering during sleep walking
- Emotional health as impact of sleep / fatigue issues
- Impact on carers and families of disturbed sleep
- Impact on memory
- Anxiety
- Risk of falls (nocturia)
- Sleep deprivation affects ability to work / learn
- Side effect of medications is sleep disruption

Ideas Generated

Opportunities generated by this group included:

- Devices to reduce noise
- Circadian glasses to address issues of sleep patterns
- A guided sleep programme linked to the environment (light and sounds) to address issues of being unable to relax by easing people into sleep.
- A caffeine monitor to address issues of too much caffeine in poor sleepers
- An orb/ball to address issues of sleepwalking by providing haptic feedback (light/sound/music) to guide the person back to bed.
- A bluetooth tracker that vibrates to address issues of sleepwalking by gently waking the person up.
- A wandering/walking chip to go inside a sleepwalker's shoes (communicates the person's position to their family, and buzzes when it passes over a threshold).
- A game to diagnose bespoke needs and change behaviours.
- A waking stimulus (e.g. noise, light, smell, vibration, pain, music, voice, loud alarm, dog barking) to address issues of sleep walking beyond the bedroom by highlighting when the patient walks into a danger area.
- A wearable alarm or tracker to address issues of sleepwalking by tracking movements and making sounds
- A tether to address issues of sleepwalking by physically preventing movement and aiding their safe return.
- A guide to get back to bed when sleepwalking.
- A sensor/mic combination to help guide a sleepwalking person back to bed. The person wears an earbud and a movement sensor patch. The patch tracks their movements and reverse the movements in audio directions through the earbud to gently guide the person to bed.
- A doorknob movement sensor to address issues of sleepwalking recognition by highlighting when the bedroom door is opened.
- A pad under the mattress or carpet to address issues of sleepwalking by identifying the patient leaving the bed.

Priority Opportunities & Ideas

1) Sleep walking alarm

This would be to identify risk, notify carers or individuals, and trigger a bespoke waking mechanism in response to the sleep walking unmet need. This is a wearable sensor that measures a pre-defined distance from the bed / safe space with a bespoke waking trigger.

Positive benefits identified as improved mental health and wellbeing and reduced risk of injury. Sleep disorders have significant impact on range of health conditions.

Potential for negative impact based on response to waking mechanism.

Next actions: focus group to review existing tech / wearables.

2) Environmental lighting in response to inappropriate sleep patterns (daytime sleep impact on night time sleep)

Arm Function

Unmet Needs & Challenges Identification

- Social isolation
- Difficult to feed – can't lift knife and fork
- Drinking
- Toileting, dressing, personal self-care
- Social interactions – shaking hands
- Cleaning and housework difficult – reliant on somebody else
- Loss of muscle in arms
- Stiffening of ligaments and tendons
- Only finger and thumb grip
- Frustration
- Anxiety
- Makes you tired
- Fear of future
- Can't travel abroad – limited to this country for holidays
- Had to leave work – arm pain and fatigue
- Less exercise and risk of weight gain
- House modifications to accommodate daily living
- Frustration in difficulty doing 'little things'

Ideas Generated

Opportunities generated by this group included:

- Focus on independence and reduced time impact on others
- Continued relationships (physical contact with loved ones)
- Controlling gadgets (although different relationship between hand and arm function)
- Mechanised toothbrush holder
- Fixed itch scratcher (fixed to table)
- Fixed gadget to wall for brushing teeth
- Adaptable mattress for rolling over in bed
- Dynamic mobile arm supporting fine finger movement
- Portable hoist – 'hoist in a suitcase'

Priority Opportunities & Ideas

- "Mech Tech for Arms" - automated arm sleeve for lifting the arms and enabling minimum arm movement allowing a person to do the most basic arm functions (scratch that itch!). Concept is an arm sleeve with rested elbow and carbon rods externally, motor driven by battery, made from materials that prevent over-heating and cold. Device could be made for specific activity or adaptable to different levels of disability. Next steps would be to convene focus group of people with conditions who would benefit.

- Voice command interface training for home management gadgets (Alexa/Siri)
- Wheelchair controller for phone usage (bluetooth enabled) to have functionality on the wheelchair to use a mobile phone. Answer through a tap/shake, call through a basic menu - very much like the model that is adapted for in car usage

Balance & Mobility

Unmet Needs & Challenges Identification

- Impact on pride
- Falls can make somebody feel embarrassed, scared, isolated, depressed, frustrated
- Can be labelled as drunk (people do not know that they have a condition)
- Limiting and impacts confidence
- Stigmatising
- Incontinence / bladder control
- Lack of control
- Misbehaving body
- Losing ability to walk
- Impact on what somebody can wear
- Lack of balance can lead to falling
- Muscular weakness
- Support equipment for shoulder/hand issues
- No more spontaneity
- Showering / washing / dressing
- Exercising in bed
- Breakfast preparation (frustration and longer)
- Travel (self-aware, need toilet breaks, trust in myself, journey planning, fatigue)
- Hard to do housework so reliance on others
- Re-purposed equipment for healthcare
- Public perceptions
- Have to stop working
- Compromises education and abilities
- Harder to travel and longer to plan holidays (carry bags, inform the airport/hotel etc)
- New hobbies and physio exercises
- Dual relationship of patient / carer

Ideas Generated

Opportunities generated by this group included:

- Combined back brace and crutch
- Better bespoke walking aids
- Toilet identification apps
- Upright frames
- Something to ease shoulder pain
- Something to reduce strain on arms / shoulders / hands when using crutches
- Clothing adaptations
- Modular / collapsible / retractable / bespoke crutch for specific tasks
- Better handle shapes on crutches

- Phone app to record factors that contribute to falling
- Futuristic gyroscope walking aid
- Power pack crutch – extra power to move forward when fatigued!
- Leg stick walker that runs along the legs – reduces strain on back
- Frame to help posture for bad backs and shoulders
- Brace to support shoulders
- National access app for toilets / shops
- Coloured button to denote need for toilet due to illness
- Notice in windows denoting disabled facilities or not

Priority Opportunities & Ideas

- Collapsible bespoke crutch which adapts with disease progression

- Arms-free gyroscopic discrete walking device with modular design for disease progression. Modular and easy to wear and supports trunk and shoulder, enables better balance and adjusts. Arms-free, unobtrusive, remain mobile, lightweight materials, and easily wearable under clothing.

Monitoring

Unmet Needs & Challenges Identification

- Measurements of muscle tone during exercise
- Difficulties with movement/walking/standing
- Difficulties standing for long time
- Can't sit for too long in the car
- Fatigue during exercise
- Muscle stiffness affects movement
- Depression/mood
- Lack of immediate feedback for self-management or carers' support
- Unnecessary meetings/interventions
- Information about good/bad days
- Required support for certain activities
- Challenge to remember sequences for people with cognitive difficulties
- Influence on relationship with partner
- Sharing/communicating key data to the right people
- Information about muscle tone
- Privacy

Ideas Generated

Opportunities generated by this group included:

- An app with tailored advice for patients/clinicians
- An activity monitor to identify daily changes in activity and long-term progression
- Wearable belt to monitor fatigue
- A device to monitor good compliance/engagement
- A smart watch to monitor patient activity
- Personalised exercise programme in a smart watch
- Exercise plan to increase muscle tone
- Monitoring system to provide feedback: subjective or inaccurate info and objective long-term measurements
- Programme that prompts parts of food preparation (difficulty, sequence…)
- System to monitor progression in dementia for remote monitoring
- Smart watch that emits sound informing of muscle tone
- Sensor arm band for fatigue monitoring
- Adhesive/plaster to change colour with muscle tone
- Mirror providing real-time feedback and displaying data (heart-rate, environment, temp…)

Priority Opportunities & Ideas

Neurological Interactive Mobile Biometric and it is Yours (NIMBY)

Who uses it and when?   Person with neurological condition uses it during the day

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How do they use it?   Wearing it (passive monitoring)

What is the biggest positive?   Real-time feedback (helpful, useful)

What is the biggest risk?   Privacy

Thoughts on manufacturing or cost?   Make use of existing tech (apple watch, alexa, mobiles…)

What don't you know?   Need to understand even better the end user's needs

Next steps? Funding ideas?   Focus groups (end users) and prototype with existing technology

Key message to take away   Led by end users. End users agree/control every stage: requirements, specifications…

Environment

Unmet Needs & Challenges Identification

- Smarter and quicker communication aids (recognise contexts and adapt vocab menus)
- Smarter home environments to learn user routines
- Traffic lights which people with physical difficulties can access
- Clock which can be seen from bed (but not constantly projecting)
- Rotating table (to access different equipment at different times)

Ideas Generated

Opportunities generated by this group included:

- Aids to use smart tech to recognise different environments and then pull up relevant (predicted) vocab in order to speed up the process of constructing messages, as it is very frustrating when people do not allow sufficient time. Can aids be smarter in order to recognise different rooms, settings and/or people in order to select relevant vocab lists to make inputting of messages more efficient
- Smarter home environments using AI to learn user routines. Currently voice activated environmental control systems which often cannot work on dysarthric speech. Possibly internet of things, or AI to learn user patterns at different times of the day.
- Clock which projects on the ceiling (as some do now BUT which doesn't project constantly) to permit better sleep while maintaining ability to see the time from bed
- Rotating table - no ideas during the meeting as to how this could be achieved - unmet need relates to accessing different items at different times of the day

Priority Opportunities & Ideas

- Traffic lights which can sense the approach of someone in a wheelchair, to enable them to move about the environment independently and safely. Possibly smart chip or QR code on chair or sensor plate under pavement on approach to traffic lights. Another possibility might be a card given to user, with a smart chip on the card. Could utilise near field tech or RFID?

Remote Support

Unmet Needs & Challenges Identification

- Cognitive decline - support for activities of daily living
- Loneliness - not feeling different, peer support
- Continence (alert and management)
- Daily living - bills, medication, appointments, social life, support network (healthcare and peers)
- Hospital At Home (access to hospital, travel to hospital, environment)
- Disability (access to mobility aids that are lighter and 'cooler', a log of accessible places, peers groups, social activities)
- Forming and maintaining relationships with restricted mobility
- Important information (facial contract during communication - this is not possible on websites and phone calls)
- Self-assessment - how to figure out how you feel. Assess your condition if you are on your own.
- Lack of independence
- Stroke: Speech, sight
- Facial palsy (face freezing in half)
- Tremors
- Gait and balance
- MND affects younger people with Parkinson's effects
- Progressive disability
- Mobility (MS)
- Continence
- Sexual health
- Cognition & comprehension (Parkinson's and Dementia)
- Hair loss
- Breathing and swallowing independently
- Autism 'living in your own world'
- Lack of sleep can affect the whole day
- Waking up confused (dementia)
- Physically getting out of bed (muscular issues)
- Self-assessing how you feel and deciding which medication you take, how much, and how you take it
- Problems eating during mealtimes
- Speech recognition
- Navigating the home
- Dealing with being a 'person' - fixing daily problems such as bills, utilities, internet
- Communication without facial contact (Expressions, lip reading, context, deafness)
- Lack of transport can be isolating
- Having fun, socialising, relationships communication

- Being away from home becomes difficult - moving things around (stuff & medication)
- Weather conditions affects condition and mobility (also consider driving)
- Dignity
- Not wanting to stand out, being normal, wheelchair needs
- Specialists needed for extra support at school, work
- Peers and siblings - conflicting family dynamics

Ideas Generated

Opportunities generated by this group included:

- Social App 'My MS/MND/PD/Stroke' that addresses issues of loneliness/fitting in/relationships by access to peer support networks. Aimed at younger neurological sufferers, highlights peer groups, accessible places, forums, societies.
- Daily monitoring system to track advancement of conditions.
- Video chat with specialists that addresses issues of limited access to hospital and limited travel support available. Video chats allow for face-to-face discussion and physical reactions, replacing phone calls and websites.
- Hospital at home that addresses issues of access/travel/environment by providing clinical access at home. Useful for OP app, assessments, clinical measures, advice, revising medication.
- MYDAY" that addresses issues of managing daily living by organising living. Includes scheduling, reminders, assistance, alerts to companies, medication plans, mobility assessments.
- Hospital at home - a mobile van kitted out for regular monitoring or interventions.
- A robotic buddy to help manage daily life - something which acts as an intermediary to facilitate doing all the paperwork/phone calls.
- A remote clinic that addresses issues of people not being able to travel to hospital by doing it by video.
- Structure, condition-specific peer support at home, that addresses issues of isolation / self-management best practice by positive psychology.
- Continence alert and support that addresses issues of accidents by identifying a need, then either signposting to the nearest toilet or delaying the urge.
- The Toilet of the Future'

Priority Project

- Time to Go – range of products (technology and clothing) to achieve continence with dignity
Part one: A wearable device that monitors your bladder capacity and send you an alert when you will need to start thinking about finding a toilet (an early warning system - 'Plan your pee with time to go'). Reduces stress of planning so much and increases freedom of movement.
Part two: Quick release to remove clothing and move it away when in a rush to use the toilet. Underwear makes this a 2 stage process currently, especially for women. Drawing on ideas of 'fashion for the disabled' or clothing that exists to make things subtle (i.e. breastfeeding tops). Must be discreet so any mishap needs to be hidden, with extra material

to replace stained or wet material and must be low cost. Clothing is fashionable and easy to use regardless of mobility and dexterity.

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Feedback

Was the session content what you expected today?

- Yes better than expected
- No expectation on arrival so good
- Much more interactive and creative
- Not really sure what I expected but was very interesting
- More interactive but was very interesting
- More interactive then I had expected – which was a good thing
- Expected more available equipment

Were activities easy to follow?

- Very easy to follow
- Very clear of what the activity of each group was
- Very well participated – perhaps different ideas could have been developed further by individual workshops by finding others who are interested in same area

Most valuable part of the day

- Discussions with patients and other members of the group to develop ideas
- Group interaction
- Being creative rather than operational for an afternoon
- Bit where we developed the idea
- People's interesting ideas
- Group feedback listening to people's ideas
- Meeting and developing ideas
- Working up unmet need and discussion
- Hearing clinicians views of unmet need
- Exposure to people with broad range of experience
- Networking and sharing idea
- Able to develop an idea relevant to a person in the group – he had lots of ideas about what was needed
- Listening to all ideas
- Well-structured build up
- Collaborative working
- Presentation from each group

Least favourite part of the day

- Initial lectures
- The "getting to know you" stuff
- Heat
- Would have benefited from having an organiser

Best way for sharing ideas going forward

- Google Drive – 4
- Private LinkedIn Group – 3
- All of above – 2
- Shared email – 4

Anything else to add?

- A very memorable day. I will cherish this experience. Developing a device needs input from patients and you did that very well.
- Very enjoyable and well delivered
- Maybe a # was needed to promote the afternoon. I'd like to know how the ideas develop further
- Atmosphere and mix of people there was good
- There is always hope
- Good to feel involved
- This was a great opportunity to gain insight into peoples lived experiences of living with long term neurological conditions as well as clinical expertise and tech development. Well done.
- Great to be involved in a group of people sharing ideas and thinking out of the box.
- Excellent experience for a carer of LTNC to give ideas of how to help people with disabilities
- Good to have more networking time
- Make good use of 'users'