People Driven Digital Health and Wellbeing #PdDigital15
White Paper / June 2015

How can we unleash people driven digital health and wellbeing?

@mjseres Arguably the first truly people led tech event happening here in Leeds **#PdDigital15**

@tobite_e Finally a health tech day not driven by the industry, but by the people #peoplepower **#PdDigital15**

@jamesfm55 People-driven digital health feels like a movement whose time has come. And much needed **#PdDigital15**

Introduction

The Five Year Forward View (October 2014) sets out a clear direction of travel for the NHS that includes raising our game on health technology and radically improving people's experience of interacting with health and care. To achieve this ambition, Personalised Health and Care 2020 (November 2014) creates a framework for use of data and technology that is grounded in collaboration:

> *The achievement of this vision must be based on a collaborative approach, rather than a centrally driven plan or strategy. The solutions and services must be defined by the service users, the carers and the care professionals, and not by technology ideologues. The process must be open and transparent, recognising the interconnectivity and mutuality of common purpose that brings together all the providers and commissioners across the care system, whether from the public, independent or voluntary sector.*

People Driven Digital Health and Wellbeing #PdDigital15 aimed to identify how we build this collaborative people-centred approach. Taking place on 13 and 14 May 2015 at the Open Data Institute in Leeds, a simple question framed the event:

'How can we unleash people driven digital health and wellbeing?'

It was an event led by and orientated around people accessing services, whose voices are often less heard than those of professionals and industry. It was an event that aimed to focus on people first and technology second. Without people at the centre, we believe that the big aspirations for digital technology in health and care will not be fully realised.

Top #PdDigital15 messages

#PDDigital15 demonstrated that people driven innovation is already alive and well - the challenge for health and care providers and commissioners is how to best work with the assets and energy of innovators who are creating the future. The top five messages from **#PdDigital15** are:

- **Ground up innovation must be recognised, understood and actively supported -** there is a strong desire for more opportunities which enable people from different backgrounds and situations to connect, network, learn and re-imagine health and wellbeing enabled by digital tools and services. We need to harness this energy and enable it to flourish. This must be led by people but supported by organisations.

- **Joining the dots -** it is vital to connect innovators and people accessing services together with practitioners, service providers and commissioners who take decisions about the future of health and care. Tension between the disruptive potential of people-led digital and

more conservative tendencies of services needs to be recognised and power shared.

- **Co-production -** the principles underpinning these connections should be openness, collaboration and ultimately co-production - this is about creating a very different set of relationships.

- **Getting the basics right -** collaboration needs to be underpinned by the right technical infrastructure to enable digital innovation (for example, interoperability between information systems).

- **Support for innovators -** digital innovators need new forms of support with access to data insights and business advice.

People driven digital innovation must be done *with* people - it can't be done *to* people.

Summary and recommendations

In this section a summary of conversations, with key recommendations, is set out. Much of what you read will be familiar and many issues, such as technical integration, are already being addressed by the National Information Board.

The right topic at the right time: The question of how to unlock innovation and also people powered solutions has never been more relevant – and there is now a community of people who wants to make sure it happens. The system may be listening: While a lot of what we discussed was about disruptive innovation on the outside there are signs that the system is ready to be disrupted. [quote from Catherine Howe's blog]

The strongest overarching theme emerging from **#PdDigital15** is that people want more opportunities that enable people from different backgrounds and situations to connect, network, learn and re-imagine health and care enabled by digital tools and services. It is through these connections that sparks occur and ground up innovation emerges - from the passions and experiences of everyday people. Some of these connections may be face to face and some may be virtual. This must be led by people but supported and enabled by organisations.

Below is a summary of key recommendations emerging from #PdDigital15 that we want NHS England, as well as commissioners and providers to give serious consideration to:

Digital entrepreneurs need...

- **Connections with the right people:**
  - An engaged health and care sector as well as the third sector
  - A means to share learning about what doesn't work as well as what does
  - Opportunities to meet and understand the needs of providers and commissioners of services

- **New forms of financing:**
  - A means of crowdsourcing help, funding and resources
  - Innovative seed funding models to develop ideas and opportunities

- **Access to the right support and skills:**
  - Practical help and advice for digital innovation from other innovators who are perhaps further ahead on their development curve
  - Collaborative space for creative thinking to imagine the possible

- **Access to specialist support in key areas:**
  - Business support to develop and deploy sustainable digital tools and services
  - Help to market research and assess evidence
  - Help to systematically measure impact and evaluate
  - Help with legal advice around issues such as information governance, intellectual property and liabilities
  - Guidance and standards for the development of digital tools and services

- **Change within the market they are trying to develop for:**
  - Rapid and rigorous - systems that can work more flexibly (for example, R&D and procurement)

- **The right technology infrastructure to work with:**
  - Easy integration for digital tools and services with electronic patient records
  - An ecosystem of reusable components using common standards that can be re-used and repurposed
  - Access to good anonymised data from which to build digital tools.

People want to be involved...

- As partners, and sometimes producers, in ground-up digital innovation which involves people at every stage
- In co-producing quality criteria for rating digital tools and services
- In the groups and committees deciding the way forward for digital in health and care
- In defining what 'good' looks and feels like
- In co-creating a digitally enabled future for health and care where their voices are at the centre.

What people want from digital tools and services...

- Accessible and reliable information about what is available
- Well designed products that are intuitive and easy to use
- Person at the centre of their care owning their own records
- More control of our health and wellbeing - opportunity to self-monitor and manage in between appointments

- Help and guidance to judge quality of digital tools and services
- Improved digital literacy for health and care staff.

People are concerned about...

- Practitioner reluctance to understand digital tools and services
- Being overwhelmed by the number and variety of social media, digital tools and services
- Privacy, security and surveillance - understanding who owns the data and where it goes
- Digital tools being bolted on to services that aren't working
- Inadvertently increasing digital inequality and leaving some people behind
- Tension between industry motivation for profit and the public sector.

People want the following underpinning principles...

- Collaboration and co-production - ask us what we want and let us collaborate and develop thinking beyond the usual constraints
- Outcome focused - digital tools and services should enable us to be active and empowered
- Culture change - digital tools and services as part of redesigned services
- Control - of our own data
- Digital equality - access to digital tools and services for the people who would most benefit from them but might be least likely to access them.

In conclusion, the conversations at **#PdDigital15** which are summarised in this paper, give some clues and some challenges as to how a collaborative approach to digital innovation, as set out in Personalised Care 2020, can be realised. The potential for people driven digital innovation from the ground up should be recognised, understood and supported at a strategic level. Health and care need to enable this to happen but it should be led by people not by institutions. It is only by people driving digital innovation that a step change can be achieved and outcomes in health and care transformed.

To read the full report please visit 🔗 [http://www.mhealthhabitat.co.uk/pddigitalwhitepaper]

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Links:

5 Year Forward View:
[http://www.england.nhs.uk/ourwork/futurenhs/5yfv-exec-sum/]

Personalised Care 2020:
[https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/384650/NIB_Report.pdf]

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