



**British Heart Foundation
Data Science Centre**

Led by Health Data Research UK

Workshop report – How can consumer wearables transform our understanding of cardiovascular disease?

JANUARY 2022

Workshop report – How can consumer wearables transform our understanding of cardiovascular disease?

Table of Contents

CONTENTS

Table of Contents.....	2
1 Executive Summary.....	2
2 Background and aims.....	3
3 Workshop summary.....	3
3.1 Workshop organisation.....	3
3.2 Workshop sessions.....	3
4 Workshop “topic” sessions in detail.....	4
4.1 Opportunities.....	4
4.2 Representativeness and validity.....	5
4.3 Scaling up and linkage.....	7
5 Workshop debrief with patient and public representatives.....	8
6 Conclusions and next steps.....	8
7 Acknowledgements.....	10
8 References.....	10
9 Additional material.....	13
Appendix A – Agenda.....	13
Appendix B – Workshop attendee list.....	15
Appendix C - Text extracted from breakout board summaries.....	18
Appendix D - Screenshots of all breakout boards.....	22
Appendix E – Word clouds of input from breakout sessions.....	35

1 Executive Summary

The use of data from wearable devices could transform cardiovascular research and healthcare, but faces many challenges such as data privacy, linkage to health datasets, accuracy, and health inequalities. We report the findings of a 2021 workshop held by the British Heart Foundation Data Science Centre involving multiple stakeholders including patients, clinicians, researchers, policy makers and wearable developers. We propose a UK-based large scale research collection of wearable data linked to healthcare data that would place the UK and NHS in the forefront of this critical area.

2 Background and aims

Traditional understanding of traits such as physical activity, heart rhythms, sleep and their health consequences has relied on either self-reported data sources or on snapshot, short-term (<14 days) device measurements. The recent explosion in sales of wearable devices means an estimated 13 million people in the UK use wearable devices in 2021 (~8.5 million active users), a rise of 7% from the previous year¹. The importance of wearable devices in health was recognised in the 2018 UK Chief Medical Officer Annual Report² and the 2019 Topol Review³. This competitive market has resulted in ever improving devices that can continuously and non-invasively measure aspects of cardiovascular health, such as physical activity⁴ and atrial fibrillation⁵. However, wearable datasets are currently of limited value to cardiovascular disease researchers as no large-scale study has established linkage of longitudinal wearable data to major clinical outcomes. As a result, this potential vast volume of valuable information on the health of UK citizens is currently inaccessible for research of relevance to clinical practice and public health policy.

There is an opportunity for the UK to take a leading position, in which large numbers of users of wearable devices share their data, linked to their health data, for medical research. Such a linked dataset could transform our understanding of the causes and consequences of cardiovascular disease. However, there are many challenges in realising this vision. These include: establishing trust and transparency with users, developing consent procedures, understanding population representativeness⁶, harmonising data across devices⁷, establishing validity of measurements⁸, performing linkage to appropriate healthcare and other relevant databases, establishing how and where data should be stored, and who should have access to such data.

To explore the creation of a population scale wearables dataset with linkage to health records, the British Heart Foundation (BHF) Data Science Centre organised a workshop with the following aims:

- To bring together the wide community of stakeholders
- To build consensus towards realising a population scale wearables dataset with linkage to cardiovascular clinical outcomes
- To define the challenges and identify key areas of opportunity
- To discuss how best to build on commercial activities in this space

3 Workshop summary

3.1 Workshop organisation

The workshop was held virtually on 17th and 18th May 2021 and brought together over 70 invited representatives from across relevant stakeholders, including wearables and app developers and producers, health data science researchers, data custodians and health policy advisors. Six patient and public representatives attended the workshop, with the expectation they will work in partnership with the BHF Data Science Centre in this area and be involved in co-production of this initiative.

3.2 Workshop sessions

The workshop was organised as three “topic” sessions (Table 1). Each “topic” featured talks from invited speakers with expertise in this area, followed by an interactive breakout session to enable broad and open discussion and to gather input from all participants. During the breakout session, workshop participants were split into 5 groups, each with a chair and additional facilitator. Participants were prompted to provide input around questions on each “topic” (table 1). The input from all breakout groups across the three “topic” sessions is summarised in Figure 1. Additional detail on each “topic” session is included in section 4 (Workshop “topic” sessions in detail) and section 9 (Additional material).

Topic	Breakout session question(s)
Opportunities	What are the big cardiovascular challenges that could be addressed with mobile health technologies?
Representativeness and validity	How might we... <ul style="list-style-type: none"> • Increase diversity and inclusion across the user base to increase representativeness of the wearables data in order for results to apply to the whole population? • Ensure the quality and accuracy of the data? • Create solutions that people want to/are able to use?
Scaling up and linkage	What are the challenges to scaling up these opportunities and why? How might we link wearables data to NHS datasets? What are the concerns/challenges of linking/sharing data (across technologies, organisations, privacy permissions etc) that we need solutions for?

Table 1. Workshop “topics” and breakout session question(s)

The three workshop topic sessions were followed by a final session, which brought together the input from the breakout sessions, and featured a chaired panel discussion towards building consensus and identifying next steps.

4 Workshop “topic” sessions in detail

4.1 Opportunities

The first session discussed the opportunities that wearables offer in addressing cardiovascular disease, with discussion and breakout board comments focused around the themes listed below:

- Opportunities to think differently
- Collection of new “types” of data
- Research opportunities
- Potential impacts

Wearables present distinct opportunities compared to traditional approaches of capturing physiological and behavioural measurements for research, enabling continuous monitoring in the real-world, at population scale and with increased granularity. A key point highlighted in the workshop was the opportunity that the unique aspects of wearables present to re-think, and re-design the questions we ask, studies we carry out, and methods and models we use, to ensure we are utilising wearables to their full potential. This will require thinking about implementation in the long-run and designing the workflow and systems from scratch, rather than trying to fit wearables data into current ways of working.

The UK is in particularly well positioned to enable linkage to clinical outcomes at population scale, due to its healthcare system covering the entire population throughout their life, providing near-complete coverage. The opportunities for such a dataset in cardiovascular disease research were discussed during the first session. These include identifying, and more accurately assessing, risk factors and digital biomarkers, providing information on temporal disease trajectories and co-morbidities, and improving clinical trials. The potential impacts are wide-ranging and far-reaching, including improving treatments, prevention, and management of cardiovascular disease, driving life-style modifications,

influencing public health policies and empowering individuals to have greater engagement in their health. The impacts are likely to be wider than cardiovascular disease and its risk factors, potentially to a broad spectrum of human disease⁹.

The creation of a cohort of wearables data linked to healthcare data and clinical outcomes requires three key components:

1. Participation of individuals
2. Wearable devices capturing physiological, behavioural and other measurements
3. Bringing together data from wearable devices and health records at scale sufficient to answer important research questions

4.2 Representativeness and validity

This session focused on ensuring data is representative, valid and accurate. The discussion and breakout session comments in this session can be divided into two main topics: 1. Participation of individuals and 2. Data validity and accuracy.

Participation of individuals

The key themes coming out of the workshop on this topic were:

- Creating a representative dataset
- Recruiting and retaining individuals

Creation of a useful cohort requires recruitment of a large number of participants. During the workshop we heard from several stakeholders with experience in this area, including MyHeart Counts¹⁰ and the Apple Heart and Movement Study¹¹.

The main challenge identified by these studies was recruiting enough participants and then retaining them throughout the study. To attract participants, there must be obvious and clearly communicated value associated with taking part, either personal or altruistic. The study must be advertised through marketing channels that will reach the desired user base (i.e. current and potential future wearables users), ideally with any required apps being endorsed by the wearable manufacturer or available through the official app route, with a low bar to participation. It is also vital that the wearable devices and any apps involved are designed so participants want, and are able to, use them. It was suggested that user focused design be employed to ensure this. Once recruited, participants need to be retained. Creating a way for participants to experience what the study is about and to feel involved increases engagement and participant retention. Study co-design and co-development are important ways to help achieve this.

It was noted that the incentivisation strategy used could bias the recruitment of participants, as different rewards will attract different people and sectors of the population. The incentivisation strategy therefore needs to be designed to minimise bias; using multiple incentivisation strategies not only reduces bias but also widens participation.

To ensure research results are applicable to all subsets of a population and that all individuals can benefit from advances, it is essential that the cohort is representative of the population. However as discussed in Tessa Strain's presentation on "Who uses a wearable device in the UK?", wearables users are not directly representative of the population⁶. Weighting assumptions can be used to minimise selection bias; however, accurate information is needed on population stratification, particularly around the behaviours or measurements of interest.

Two alternative models of recruitment were considered: 1. creation of a new cohort through recruitment of existing wearables users and 2. augmenting an existing cohort (e.g. UK Biobank¹² or Our Future Health) with the addition of wearables data. There are approximately 8.5 million active consumer wearables users in the UK, representing a huge potential cohort population. However, as mentioned above, wearables users are not representative of the general population. Augmenting an existing cohort would be limited to the individuals who are already part of such a cohort. This could present some advantages, with study recruitment response rates from existing cohort members likely to be higher than from the general population. Also, existing cohorts are likely to include additional data, for example genomic and deep phenotypic information. However, this model of recruitment would limit the potential cohort size. In addition, existing cohorts are themselves not representative of the general population. For either of these models of recruitment, co-design with public partners will be important to maximise participation.

The topic of cohort representativeness generated highly engaged discussion and rich input. Suggestions to increase participation of under-represented sections of the population included providing free devices to participants or making them available at a reduced price, targeted marketing, focused engagement and recruiting community champions. Working with our patient and public representatives, we will seek additional input on how we could make the dataset as representative as possible.

The number of individuals required in such a cohort will depend on the questions being asked - for example, a much larger cohort will be required to study rare clinical outcomes. It will be important to carry out power calculations to estimate the cohort size required to answer a range of questions of interest.

Data validity and accuracy

The key themes coming out of the workshop on this topic were:

- Ensuring data comparability across devices and individuals
- Validity – how accurate are measurements
- Metadata

The options considered for supporting data capture from wearables devices fall into two categories: 1. 'bring your own device' i.e. capturing data from a range of consumer wearables e.g. Fitbit and Apple Watch already owned by the user; or 2. providing individuals with a common device as part of the study. The suitability of each of these approaches depends on the model of cohort recruitment. Augmenting an existing cohort with wearables data could be supported by providing a common device to participants, allowing potential participation of all cohort participants. However, providing wearables devices would limit the cohort size due to cost, limit the timespan of data capture, and partly remove some of the "real-world" advantages of capturing data from existing users. Creating a wearables dataset from existing wearables users would be best facilitated by supporting capture from a range of consumer wearables, allowing potential participation of all wearables users. An additional advantage of this is that all common consumer devices support sharing of the data to 3rd party apps, by, and with consent of, the wearable user, with the additional potential to access historical data.

Bringing together data from a range of devices introduces challenges. During the workshop, Richard Dobson presented RADAR-base, an open-source platform that ingests data from different health monitoring devices at scale. RADAR-base pulls data from different sources (e.g. from wearables via application programming interfaces (APIs)), organises and processes the data, and extracts parameters that are used to generate physiological measurements. These can be made available to data consumers, e.g. as feedback to cohort participants, or for research via a database or API.

Different devices use different algorithms, formats, output measurements and units. In addition, these algorithms and outputs will change over time, as the wearable manufacturer innovates, develops new products and releases updated software. It is unrealistic to expect consumer wearable device companies to standardise algorithms, as this is where they innovate and compete. Therefore, harmonisation is required to ensure data is comparable and interoperable across devices¹³.

Questions were also raised about data validity and accuracy: how accurate are wearables measurements, and is this dependent on the individual wearer, context and device? It was agreed that setting up a large-scale cohort would require ongoing validation and benchmarking studies, comparing devices across individuals with different characteristics and lifestyles. The validity of wearables data will also depend on the consistency and representativeness of device usage, both across the population and within individuals. For example, wearable use may be increased if the user is actively trying to increase their fitness or training for a sporting event. It will therefore be important to promote consistent usage by cohort participants, to keep participants engaged and emphasize that all wear is valid.

The importance of capturing device-specific (e.g. manufacturer, model) and individual-specific (e.g. sex, date of birth) metadata was discussed. Such metadata will be essential to detect and correct for confounding factors.

4.3 Scaling up and linkage

This session considered the requirements and challenges associated with bringing together data from wearable devices and health records at scale. The key themes that came out of this session were:

- Linkage
- Consent
- Concerns about privacy and need for public trust
- Considerations of population-scale research

Realisation of the opportunities discussed in session one will require linking of the data from each individual's wearable device to their own health records. As mentioned above, the UK is particularly well placed to facilitate this, with a single national health service (NHS) that covers all the population throughout their life. Within the NHS, everyone has a unique NHS number that can be used to link data across health records¹⁴. The consensus was that an individual's NHS number could be used to link wearables data to health records, with cohort participants invited and enabled to provide this, along with additional personal information (e.g. name and date of birth) that could be used to confirm correct linkage, ideally at the point of consent.

The need to develop an electronic informed consent process was discussed. This must provide clear and transparent information about what data the participant is sharing and exactly what the data will be used for, to enable the participant to make an informed decision. It was felt that wearables users expect to retain ownership and control of their data. This should be considered in the design of the consent process, possibly with different levels of data sharing or types of studies that the data can be used for.

There are privacy concerns associated with the sharing and access to personal data. This is particularly true for confidential health data. It is essential that all data are securely transferred and stored, conforming to all legislation relating to information governance and best practice. It was recommended to obtain trusted independent advice regarding data security. Gaining and maintaining public trust will be key in the success of any such project. Suggestions for developing public trust included making available informational resources on all aspects of the initiative, encouraging

conversation in the public domain around data sharing for health research, and community involvement, including in co-production of the project.

During this session, considerations of population-scale research and the logistics of handling “big data” were discussed. The wearable devices and supporting infrastructure must support scaling-up, e.g. uploading wearables data and harmonisation of data at scale. It was felt that the research questions asked should focus on those for which a population scale dataset can make the most beneficial public health impact, in terms of improving disease outcomes, driving healthier behaviours, or influencing health policy. Workshop participants suggested that we take learnings from how other areas of research have involved patients and the public in co-production of studies, particularly around research questions, scaling up and linkage.

5 Workshop debrief with patient and public representatives

We carried out a post-workshop debrief with the patient and public representatives, during which we obtained feedback on the workshop, presented our initial project proposal for feedback, and discussed next steps. The key points to come out of this meeting were:

- An agreement on the proposal to initially focus on existing wearables users due to the advantages this approach offers, with a caution to be mindful that this is a self-selecting group
- The need to have clarity on the research questions we are aiming to answer and communicate this clearly to participants
- Being clear to explain the benefits and risks to all involved
- The importance of transparency and building trust

6 Conclusions and next steps

Building on the community input gathered in this workshop and post workshop feedback, we have developed a vision for the realisation of a population scale wearables dataset linked to NHS records. As there are two models for participant recruitment (creation of a new cohort or augmenting an existing cohort), each associated with different and distinct advantages, we have decided to follow a two-pronged approach;

- 1) We will focus initially on scoping the creation of a new cohort, recruiting existing wearables users, supporting data capture from the most commonly used consumer wearables devices (e.g. Fitbit and Apple). We would take advantage of the existing capability provided by wearables producers, which enables wearables users to share data from their device with a 3rd party app with their consent. Data from each individual’s wearable device would be stored within a secure research environment, linked to their routinely collected NHS health records. This would (at least initially) be for research only and not visible in routine care (until proven clinical benefit can be demonstrated).
- 2) We will also explore the potential for augmentation of existing research cohorts with longitudinal wearables data. Plans here would probably involve the provision of research-grade devices to existing cohort members, with data collection over a shorter timescale (following a similar model to the UK Biobank accelerometer substudy¹²).

We will now explore the following next steps towards realisation of this vision:

- Working with patients, the public, clinicians and other end-users to understand needs and motivators and to co-design studies and technologies
- Potential routes for collaboration with wearables developers

- Mechanisms for extracting data from devices, harmonising and linking
- Possible funding routes
- Processes for obtaining consent
- Potential routes for collaboration with existing cohorts

We recognise that the success of this initiative is dependent on developing studies and technologies that patients and the public trust, value, and are willing and able to participate in and use. Towards this, we will co-develop all aspects of this initiative with our patient and public representatives, including defining research questions, facilitation of data collection, recruitment and retention of participants, ensuring transparency and developing trustworthiness.

7 Acknowledgements

This workshop and report were produced by the BHF Data Science Centre, with the following contributions: Jackie MacArthur organised workshop, drafted and revised report; Aiden Doherty designed, co-organised and chaired workshop, revised report; Cathie Sudlow provided input on workshop design, co-chaired, revised report; Lynn Morrice provided input on workshop design, revised report; Debbie Ringham organised recruitment and orientation of public contributors, revised report; Tammy Watchorn (<https://tammywatchorn.com/>) designed breakout sessions; Lydia Martin provided organisation support. In addition, we thank the following for reviewing and editing the report: Sophie Staniszewska, Tim Chico, workshop speakers, public contributors.

In addition, the following people are acknowledged for their engagement and rich contributions to the workshop: workshop speakers, breakout session chairs and facilitators, public contributors and workshop participants (see Appendix B).

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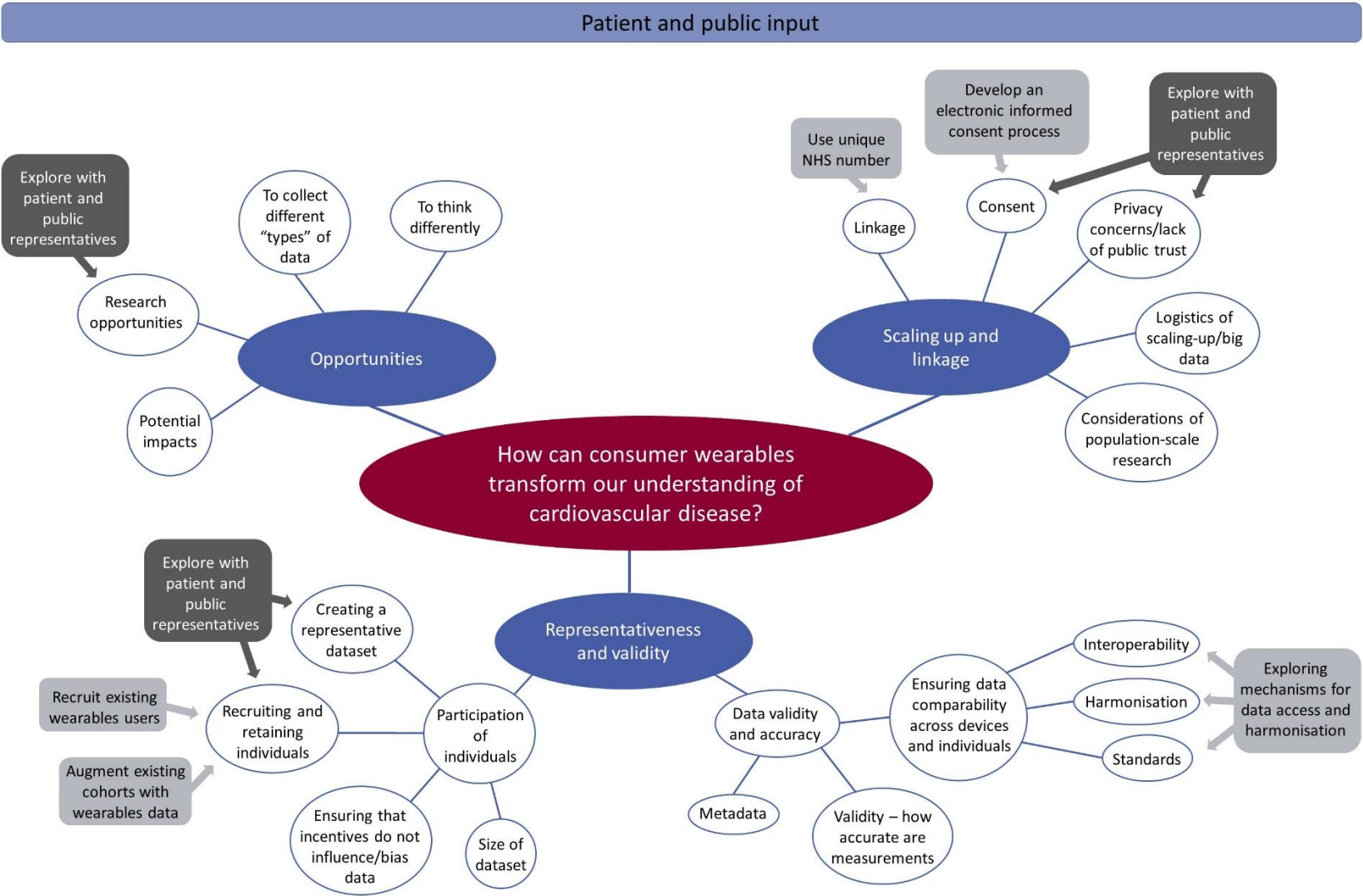


Figure 1. The workshop’s question “How can consumer wearables transform our understanding of cardiovascular disease?” was addressed in three “topic” sessions, shown in blue. Participant input on each “topic” has been grouped into themes, shown in white. The areas we plan to focus on in the next steps towards developing a pilot project are shown in grey. Patient and public input was included across all topics. In the next steps patient and public input will be explored at all points, with the steps shown in darker grey identified as being critical for patient and public input.

9 Additional material

Appendix A – Agenda

Day 1 - Monday 17th May 2021

All times are in BST

Time	Item	Speakers
14:00	Welcome & overview	Aiden Doherty, Cathie Sudlow
Session 1 – What are the opportunities with wearables and apps?		
14:05	The Covid Symptom Study App: a study of more than 4M citizen scientists, what lessons can we learn?	Carole Sudre, UCL/KCL
14:20	[Redacted] ¹	[Redacted] ²
14:35	What opportunities exist for CVD researchers to engage with UK Fitbit users?	Tony Faranesh, Aideen O’Colmain, Fitbit, LLC
14:50	Discussion	
15:00	Introduction to using Mural and breakout boards	Tammy Watchorn
15:05	Breakout session discussing opportunities for wearables data in addressing cardiovascular disease	<i>15 people per breakout, plus 1 chair and 1 facilitator</i>
15:30	Tea/coffee	
Session 2 – Who might use a wearable device and how valid is the data?		
15:45	Who uses a wearable device in the UK?	Tessa Strain, Cambridge
16:00	How well do wearables work outside of the laboratory?	Rosemary Walmsley, Oxford
16:15	How much effort is needed to integrate consumer wearable data into existing epidemiological studies?	Richard Dobson, KCL/UCL
16:30	Discussion	
16:40	Breakout session discussing the challenges and opportunities associated with ensuring data is representative and valid	<i>15 people per breakout, plus 1 chair and 1 facilitator</i>
17:10	Chairs of breakouts from session 1 and 2 report back	
17:30	End of day 1	

¹ Redacted at speaker’s request

² Redacted at speaker’s request

Day 2 – Tuesday 18th May 2021

All times are in BST

Time	Item	Speakers
14.00	Welcome	Aiden Doherty, Cathie Sudlow
Session 3 – How could we appropriately link data from wearables to clinical outcomes?		
14:05	How valid are consumer wearables for physical activity research and what insights do they give for CVD?	Euan Ashley, Stanford
14:20	What lessons can we learn to successfully link participants' data to CVD outcomes?	Marion Mafham, Oxford
14:35	What are the unique challenges of linking wearables data with clinical outcomes?	Ronan Lyons, Swansea
14:50	How can we involve patients and the public to appropriately design a study to link wearables data with clinical outcomes?	Sophie Staniszewska, Warwick Medical School
15:05	Discussion	
15:15	Breakout session discussing the challenges and opportunities associated with scaling up and linkage of wearables data to health datasets	<i>15 people per breakout, plus 1 chair and 1 facilitator</i>
15:45	Tea/coffee	
Session 4 – What should be done next?		
16.00	Chairs of breakout sessions report back	
16.25	Chaired panel discussion	Aiden Doherty, Cathie Sudlow
17.15	Closing remarks	
17.25	Meeting ends	

Appendix B – Workshop attendee list³

Name	Affiliation
Adam Steventon	The Health Foundation
Aideen O'Colmain ^S	Fitbit, LLC
Aiden Doherty	University of Oxford
Alexandra Clarke-Cornwell	The University of Salford
Alice Dowden ^B	HDR UK
Alison Elderfield ^B	HDR UK
Allan Lawrie	University of Sheffield
Amos Folarin	King's College London / South London and Maudsley NHS Trust (SLaM)
Andy Stanford-Clark	IBM UK
Annemarie Koster	Maastricht University
Anwar Gariban ^P	Public contributor
Barbara Jefferis	University College London
Beelin Baxter	DHSC
Calum MacRae	Harvard Medical School
Carole Sudre ^S	University College London, King's College London
Caroline Jay	University of Manchester
Cathie Sudlow	BHF Data Science Centre, HDR UK
Charlie Foster	University of Bristol
Chris Roebuck	NHS Digital
Dan Bamford	NHS England & Improvement
David Hunter	University of Oxford
Dylan Thompson	University of Bath
Euan Ashley ^S	Stanford
Fabio Ciravegna	University of Sheffield
Frank Kee	Queens University Belfast
Gerry Reilly ^B	HDR UK
Giorgio Quer	Scripps Research
Harry Rutter	University of Bath
Helen Grice ^P	Public contributor
Ian Boyd	NHS Digital
Jackie MacArthur	BHF Data Science Centre, HDR UK
Jade Chynoweth ^B	University of Plymouth
James Pickett ^B	HDR UK
Jay Pandit	Assistant Professor, Northwestern University

³ Includes all participants that have consented to have their name and affiliation made publicly available, in association with this workshop

^SSpeaker

^BBreakout session chair/facilitator

^PPublic contributor

Name	Affiliation
Jennifer Hicks	Stanford University
Jessilyn Dunn	Duke University
Jo Holliday	UK Biobank, University of Oxford
John Ainsworth	The University of Manchester
Katrien Wijndaele	MRC Epidemiology Unit, University of Cambridge
Kelvin Pitman ^P	Public contributor
Laura Brocklebank ^B	UCL
Luca Foschini	Evidation Health
Lydia Martin ^B	BHF Data Science Centre, HDR UK
Lynn Morrice	BHF Data Science Centre, HDR UK
Maisie Mckenzie ^P	Public contributor
Marion Mafham ^S	University of Oxford
Mark Hamer	UCL
Mark Kelson	University of Exeter
Mark Yates	Our Future Health
Marko Balabanovic	Our Future Health
Martin Cowie	Royal Brompton Hospital
Matthew Sydes	BHF Data Science Centre, MRC Clinical Trials Unit at UCL
Michael Cook	Our Future Health
Michael Parker	Ethox Centre, University of Oxford
Mike Hittle	Stanford
Mike Trenell	Newcastle University
Miranda Armstrong	University of Bristol
Naomi Allen	UK Biobank
Nicola Monk ^P	Public contributor
Niels Peek	The University of Manchester
Priya Ramanah	NHS England and NHS improvement
Richard Dobson ^S	King's College London, University College London
Richard Irvine	NHS Digital
Richard Issitt	DRIVE, Great Ormond Street Hospital
Richard Pulsford	University of Exeter
Ronan Lyons ^S	Swansea University
Rosemary Walmsley ^S	University of Oxford
Sabine Van Der Veer	Centre for Health Informatics, University of Manchester
Scott Small ^B	University of Oxford
Sebastien Chastin	Glasgow Caledonian University and Ghent University
Shing Chan ^B	University of Oxford
Sophie Staniszewska ^S	Warwick Medical School
Soren Brage	MRC Epidemiology Unit, University of Cambridge
Susheel Varma ^B	HDR UK
Tessa Strain ^S	University of Cambridge
Thanasis Tsanas	University of Edinburgh
Tim Chico	University of Sheffield

Name	Affiliation
Tony Faranesh ^S	Fitbit, LLC
Wan-Fai Ng	Newcastle University
Will Dixon	The University of Manchester
Yang Long	Durham University

Appendix C - Text extracted from breakout board summaries

Opportunities

Text extracted from summary of breakout session 1 on the question “What are the big cardiovascular challenges that could be addressed with mobile health technologies?”

- Think differently
 - Opportunity to approach this in novel ways and explore different questions
 - Will require different methods
- Collect different “types” of data
 - Scale - Population level -> rare disease
 - Length – Hours -> many years
 - Value of long-term/continuous measurement
 - Impact of real-world events
 - Coupling of personal data with healthcare record linkage to enable novel research
 - Collect data that is difficult to collect accurately via other means e.g. sleep (impact on health), quality of life, impact of noise on health, measures of stress
- Research
 - Identifying risk factors (e.g. health behaviours) – more accurate assessment of risk factors
 - Better trials
 - Prevention
 - Aetiology
 - Treatment
 - Disease management
 - Digital biomarkers for CVD
 - Temporal trajectories of disease and co-morbidities
- Potential impact
 - Drive life-style modification
 - Real-time feedback to impact lasting behavioural change
 - Self- monitoring/incentives
 - Support rehabilitation
 - Early detection
 - Monitoring adherence to interventions
 - Empowerment – greater engagement in own healthcare
 - Identifying public priorities
 - Creating communities
 - Leveraging data and relationships with key stakeholders to drive change through public health policy
 - Reducing research costs
 - Pre-operative and post-operative monitoring
 - Better care
 - Public health
 - Delivering effective health coaching for high-risk heart disease patients
 - Using risk prediction to target interventions
- Things to think about

- Opportunity to improve access and inform treatment across socio-economic backgrounds
- Develop industry standards for wearables data and work to ensure maintenance of the algorithms over time i.e., keep core datasets the same
- Working with industry and organisations to move towards a common goal of helping people lead healthier lives
- Build win-win areas for collaboration between industry and academia and provide access to raw data for research
- Learn from population, apply to individual
- Opportunity to co-design with the public
- Collect data independent of the question

Representativeness and validity

Text extracted from summary of breakout session 2 on the questions “How might we? - Increase representativeness across the user base in order for study results to apply to the whole population? Ensure the quality and accuracy of the data? Create solutions that people want to/are able to use?”.

Participation of individuals

- Creating a representative dataset
 - Support capture of data from range of devices – not just Apple, Fitbit, Garmin
 - Provide devices – through NHS, PE lessons, community alarms
 - Tax free? To be offered on NHS/tax free would need to demonstrate benefit first – however if studies are on a biased population will these fully represent/have power to detect benefit?
 - Targeted marketing
 - Community champions/buddy system
 - Engage under-represented sections of the population e.g. older adults
 - Increased under-represented outreach, public patient involvement, and provide devices to participants
 - Coverage of specific populations
 - Reaching vulnerable populations
- Recruiting and retaining individuals
 - Assess differential willingness to own, wear, share wearables
 - Benefit to users
 - Clear benefit to users - What’s in it for me? – highlight personal benefits
 - Highlight selfish and altruistic benefits
 - Provide feedback to users
 - Devices that users want to and are able to use
 - Device design
 - Gamification
 - Simplicity
 - Design devices that are easy to use
 - Intuitive user interfaces
 - Listen to public/patient input on wearable/app design and usability – not just fitness/health involved
 - Affordable

- Support for users
 - Provide training
- Identify and minimise barriers/concerns e.g. privacy, transparency
- Collect wearable data from established longitudinal cohorts with known sampling frameworks
- Size of dataset
 - Recruit, retain, consistent usage
 - How many people/data points are actually needed?
 - Depends on questions being asked
- Things to think about
 - Ensure that incentives do not influence/bias data

Data validity and accuracy

- Ensuring data validity and accuracy across devices and individuals
 - Interoperability and harmonisation
- Interoperability across devices
 - Changing technologies, different devices
 - Data standards/conversion
 - Enabling harmonisation – RADAR platform
 - Better than getting everyone to use same device
- Harmonisation
 - Harmonisation of data across devices and individuals
 - Provide device or not
 - Interoperability between ecosystems
 - Standards for data models
 - Algorithm drift
- Standards
 - Generate an objective standard for cross platform data validation and synthesis
 - Best practice
- Validity - How accurate are measurements
 - Data validity in context
 - Validation studies
 - Benchmarking, ongoing validation, comparing different devices and fine-tune device to specific individual's characteristics/lifestyle
- Promoting consistent usage
 - Keeping people engaged
 - Emphasize that all wear is valid
- Metadata
 - Device metadata are essential
- Things to think about
 - Availability of raw data

Scaling up and linkage

Text extracted from summary of breakout session 3 on the questions “What are the challenges to scaling up these opportunities and why? How might we link e.g. wearables data to NHS datasets?”

What are the concerns of linking/sharing data (across technologies, organisations, privacy permissions etc) that we need solutions for?”.

- Privacy concerns/lack of public trust
 - Education/trusted independent advice/guidance – overcome concerns re sharing/privacy
 - Using community involvement to establish trust for linkage
 - Transparency of data use
 - Data ownership
 - Wearables owner wants control – deeper relationship when needed
- Consent
 - Need for data to be aligned with consent – different levels of consent (?)
 - Methods for e-consent
- Logistics of scaling up/big data
 - Need for uploading/sending wearables data
 - Data volume
- Linkage
 - Data accessible in same place – wearables data linked to health data
 - Use NHS number
 - What information needs to be linked
 - Identity matching as a service (political, rather than technical)
- Considerations of population-scale research
 - How can we learn at population scale
 - Define use cases where it will make a tangible difference at scale
 - Focusing on the purpose; identifying what we want to achieve at scale with respect to behaviour change and policy makers
 - Look at how we can take learnings from how other areas of research have involved patients and the public in co-production of thinking around scaling up and linkage
 - RCT that shows that addition of wearable data on top of standard care improves a reasonably hard outcome; patient/clinician satisfaction, use of healthcare resource, and patient outcome
- Things to think about
 - Scaling up will be very different depending on the type of devices we are gathering data from e.g, wearables or other apps, so need to be clear on the purpose of this, whether we want to scale up in terms of numbers or scale up in terms of commitment over a longer time period
 - Should there be a single TRE for wearables data with feeds to different systems or vice versa
 - Behavioural scientists could work with software developers to drive engagement and therefore increase the quality of data over time
 - Devices designed to support scaling up
 - Passive vs active wearables
 - Just because we can use wearables for something doesn't mean we should
 - Critical mass adoption – can we start with phones activity tracking – 6 billion phones out there

Appendix D - Screenshots of all breakout boards

1. Breakout boards from session discussing “Opportunities”

Screenshots of virtual whiteboards from breakout session 1 on the question “What are the big cardiovascular challenges that could be addressed with mobile health technologies?”.

What are the big cardiovascular challenges that could be addressed with mobile health technologies?



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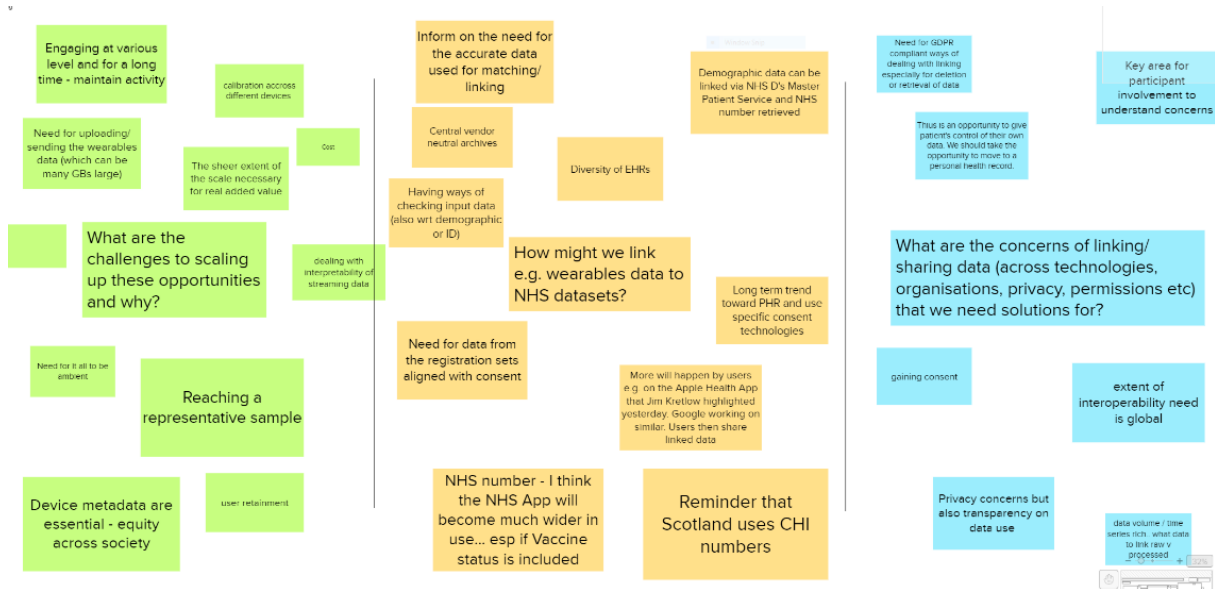
2. Breakout boards from session discussing “Representativeness and validity”

Screenshots of virtual whiteboards from breakout session 2 on the questions “How might we? - Increase representativeness across the user base in order for study results to apply to the whole population? Ensure the quality and accuracy of the data? Create solutions that people want to/are able to use?”.



3. Breakout boards from session discussing “Scaling up and linkage”

Screenshots of virtual whiteboards from breakout session 3 on the questions “What are the challenges to scaling up these opportunities and why? How might we link e.g. wearables data to NHS datasets? What are the concerns of linking/sharing data (across technologies, organisations, privacy permissions etc) that we need solutions for?”.



Engaging at various level and for a long time - maintain activity

Need for uploading/ sending the wearables data (which can be many GBs large)

What are the challenges to scaling up these opportunities and why?

Need for it all to be ambient

Device metadata are essential - equity across society

user retention

Reaching a representative sample

Engaging at various level and for a long time - maintain activity

calibration across different devices

The sheer extent of the scans necessary for real added value

Or

Inform on the need for the accurate data used for matching/ linking

Central vendor neutral archives

Diversity of EHRs

Having ways of checking input data (also wrt demographic or ID)

How might we link e.g. wearables data to NHS datasets?

Need for data from the registration sets aligned with consent

NHS number - I think the NHS App will become much wider in use... esp if Vaccine status is included

Reminder that Scotland uses CHI numbers

Demographic data can be linked via NIS D's Master Patient Service and NHS number retrieved

Need for GDPR compliant ways of dealing with linking especially for deletion or retrieval of data

Thus is an opportunity to give patients control of their own data. We should take the opportunity to move to a personal health record.

Key area for participant involvement to understand concerns

What are the concerns of linking/ sharing data (across technologies, organisations, privacy, permissions etc) that we need solutions for?

Long term trend toward PHR and use specific consent technologies

More will happen by users e.g. on the Apple Health App that Jim Kettlewell highlighted yesterday. Google working on similar. Users then share linked data

gaining consent

extent of interoperability need is global

Privacy concerns but also transparency on data use

data volume / time series rich - what data to link raw / processed



Future study participants not knowing their ID in either setting (their wearable ID or their NHS ID). Even if they can look it up, not available at the time of study onboarding - missed opportunity

(technical challenge) Data Volume, Velocity, Variety

Some challenges might be cost and time - funding and ethical approvals

Recruitment into health studies from the wearables platforms, with consent process collecting the identifiers needed for linkage

Allow people to enter their NHS number on their wearable alongside consent for linkage

Better methods for dynamic e-consent

There may also be the worry that information could be shared with insurance providers which could potentially be used to increase insurance costs if the person may not have been formally diagnosed with a condition however their participation in that study may reduce insurance / coverage or future costs

What are the challenges to scaling up these opportunities and why?

Need transparency about the linked data - who is accessing it, for what purpose?

Lack of public trust

Privacy concerns must be overcome. This could include clear consent materials whose consent is sought and an improved opt out process for use of pseudonymised data without consent. Currently people can opt out of their data being used in specific ways or for specific purposes. If people could opt out of their data being used for particular types of research (e.g. combined with de-identified wearables data or used to inform a clinical trial) then this would help them retain control over their data

Participants would need to have the option to send the raw data they are sharing. They may not want to share the same type of data throughout the whole study

How might we link e.g. wearables data to NHS datasets?

NHS unlikely to want/ need raw data. Clinically valuable outcomes generated externally and pushed to NHS (using e.g. FHIR) or data is pulled as required from vendor APIs

If the NHS designed their system they require then the vendors could design their devices to provide this data

Integration of wearables into EHR/ clinical data platforms

In the future, integrate patient-generated data into the NHS for clinically useful purposes (eg remote monitoring of LTCs) then have secondary uses (like current EHR research)

The 'datafication' of health (see Ade Lovelace report). Blurs boundaries around the governance of health data, and what health data mean if there are surrogates from consumer devices

We need a mechanism of providing transparency and resource about the use of the data.

What are the concerns of linking/ sharing data (across technologies, organisations, privacy, permissions etc) that we need solutions for?

Some commercial wearable providers already knowing lots of other things about people through other services they provide (e.g. Apple, Fitbit/Google) -

Concerns about tech giants holding info on health outcomes, to be used for commercial gain rather than public good

Access controls to allow science and promote openness but also protect participants and misuse

to help people/patients keep track of with whom their data is shared and why

loss of future control. It is unknown what safe to share today is problematic for privacy by later linkage or novel processing

Need for the possibility of setting of limits for sharing/linkage to often passively collected data. Consent might be provided desirable for sharing of limited outcomes from wearables collected during limited periods, rather than simply for continual passive data collection on as many outcomes as the device measures.

My brother was involved with a toothbrush trial through the school back in the 80s. Our full family was provided with toothpaste over a number of years and my brother had to have regular dental checkups. So involving full families in projects which could be through schools/NHS, etc you could potentially obtain buy in that way

If patients were using wearables as part of their care plan then more would be gained by the more of an uptake and involvement

There also needs to be trust. If the interface uses NHS more would be more trust than either than a vendor that is

Integrate with existing studies that have linkages or propose to have them - don't recreate the wheel. Thinking UK Biobank or potentially Our Future Health

If Apple or Fitbit recognise other Bluetooth devices then a whole number of other medical devices could upload to their health record database also. Apple and Fitbit need to enable other apps to read and write data to their health record databases. There's still many incompatible apps

continuing/maintenance informed consent with updates to hardware/ software/ functionality

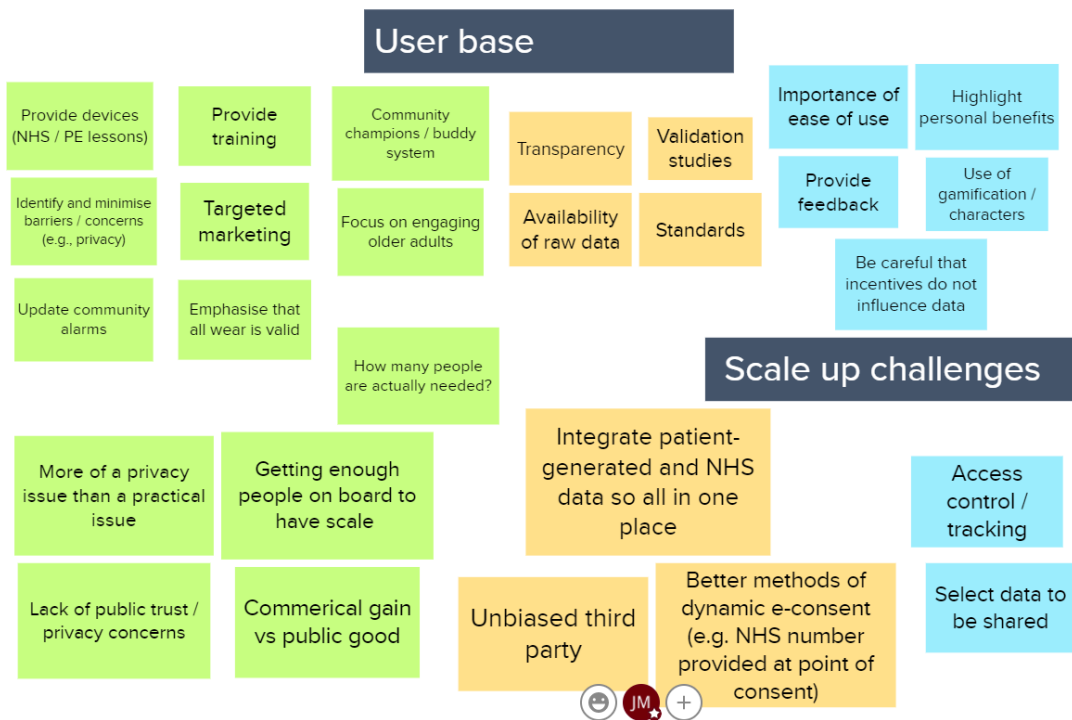
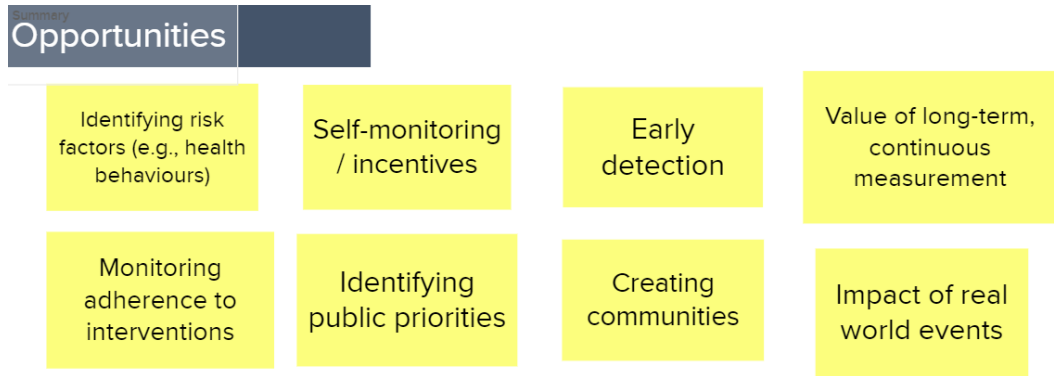
A data footprint would be helpful like credit check system. There could be a system which submits a request to the user which needs to be approved in order to access the data

BHF Data Science Centre Workshop report – How can consumer wearables transform our understanding of cardiovascular disease?



4. Breakout board summaries





Summary

Opportunities

- Generate an objective standard for cross-platform data validation and synthesis
- Real-time feedback to impact lasting behavioral change
- Coupling of personal data with healthcare records linkages for further research
- Leveraging data and relationships with key stakeholders to drive change through public health policy
- Opportunity to improve access and inform treatment across socioeconomic backgrounds
- Develop industry standards for wearables data and work to ensure maintenance of the algorithms over time i.e., keep core datasets the same
- Working with industry and organisations to move towards a common goal of helping people lead healthier lives

User base

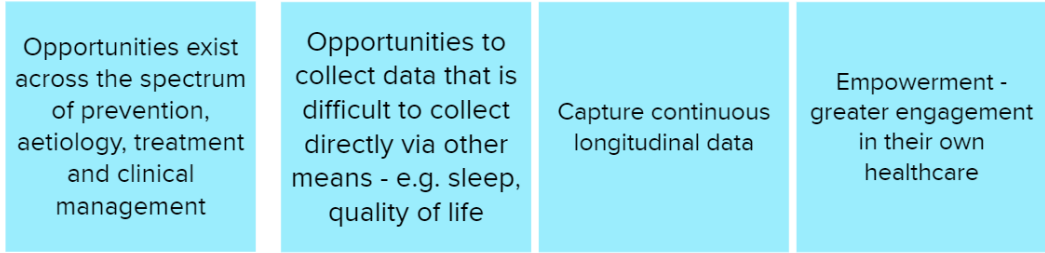
- Increased under-represented outreach, public patient involvement, and provide devices to participants
- Build win-win areas for collaboration between industry and academia and provide access to raw data for research
- Enable cross harmonisation of different wearables to improve quality and accuracy of data
- Co-design to understand barriers to participation - generating value in feedback for the user/participant

Scale up challenges

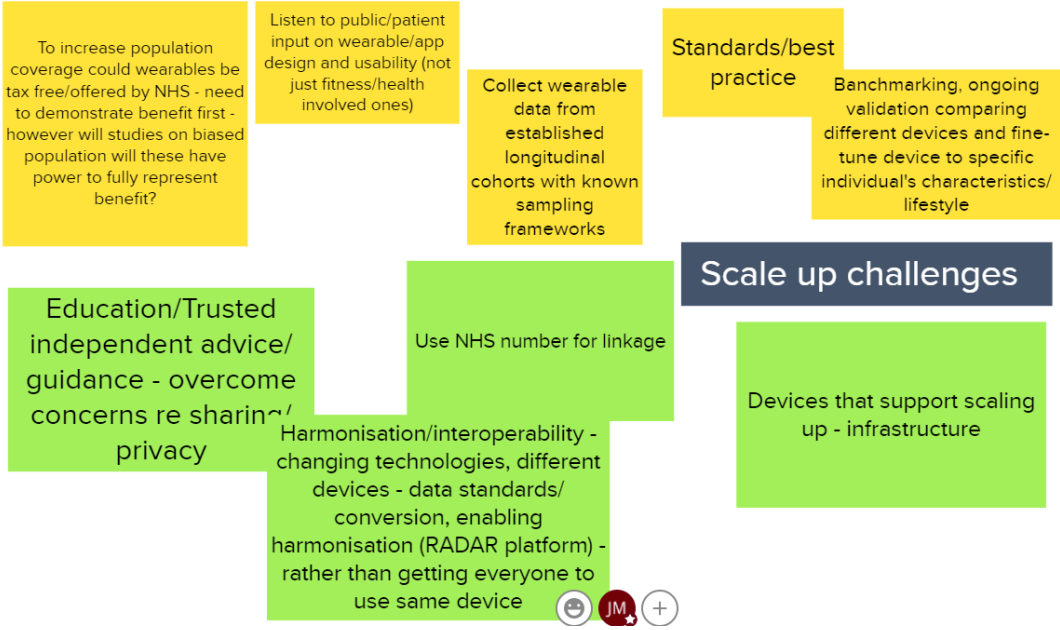
- Scaling up will be very different depending on the type of devices we are gathering data from e.g, wearables or other apps, so need to be clear on the purpose of this, whether we want to scale up in terms of numbers or scale up in terms of commitment over a longer time period
- Focusing on the purpose; identifying what we want to achieve at scale with respect to behavior change and policy makers
- behavioural scientists could work with software developers to drive engagement and therefore increase the quality of data over time
- Using community involvement to establish trust for linkage
- look at how we can take learnings from how other areas of research have involved patients and the public in co-production of thinking around scaling up and linkage



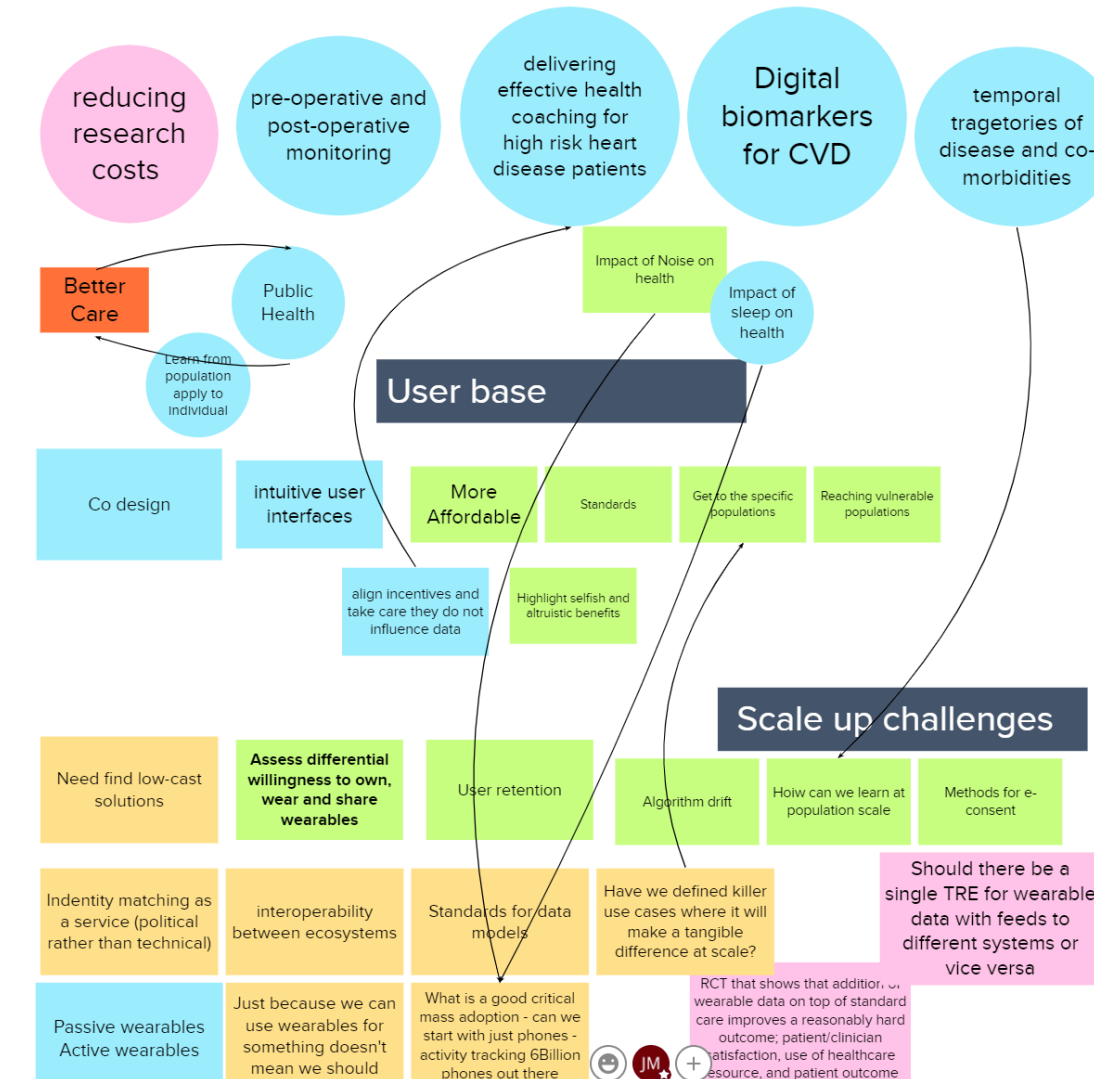
Opportunities



User base



Opportunities



Appendix E – Word clouds of input from breakout sessions



Figure E-1. Word cloud of input from breakout session 1 on the question “What are the big cardiovascular challenges that could be addressed with mobile health technologies?”

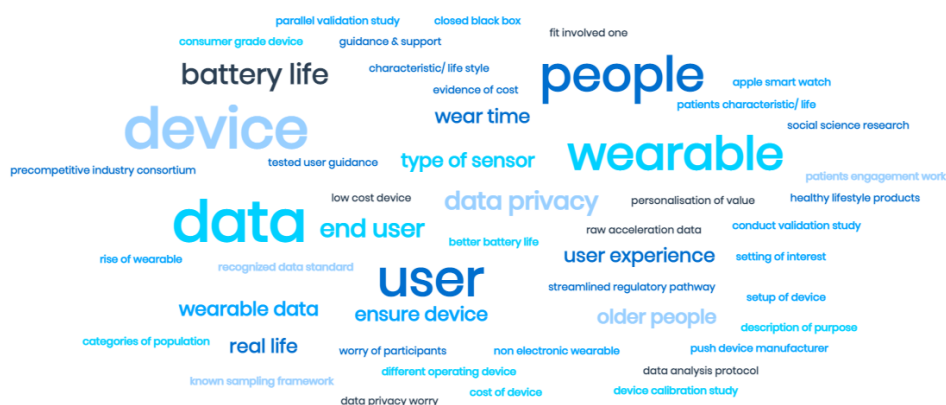


Figure E-2. Word cloud of input from breakout session 2 on the questions “How might we? - Increase representativeness across the user base in order for study results to apply to the whole population? Ensure the quality and accuracy of the data? Create solutions that people want to/are able to use?”.



Figure E-3. Word cloud of input from breakout session 3 on the questions “What are the challenges to scaling up these opportunities and why? How might we link e.g. wearables data to NHS datasets? What are the concerns of linking/sharing data (across technologies, organisations, privacy permissions etc) that we need solutions for?”.