Smartphone and wearable data in cardiovascular research: understanding the views of the public and professionals

APRIL 2024

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Summary

Smartphone and wearable data (SaWD) has huge potential to contribute to cardiovascular research and healthcare. A key aim of the British Heart Foundation (BHF) Data Science Centre is to establish a prospective, large-scale smartphone and wearable dataset linked with participants' NHS data. However, there is currently no consensus on what SaWD should be collected in such a study.

We therefore surveyed researchers, clinicians, patients and the public to define the SaWD with the most utility for cardiovascular research studies, and greatest acceptability for sharing by the public.

We identified a list of 13 measures that can be obtained from smartphones and wearables that would both support a broad range of cardiovascular research and be acceptable to potential study participants. These measures included continuous heart rate, moderate and vigorous activity and time spent being sedentary. Over 75% of public respondents were in favour of allowing the use of these 13 measures, indicating broad support for the use of these specific types of SaWD linked to NHS data for cardiovascular research.

The BHF Data Science Centre will use this list as a starting point for the creation of a large-scale dataset that can be linked to NHS data for cardiovascular research.

Background

The majority of UK adults use a smartphone, while around 40% of people use wearables such as fitness watches, and these figures are steadily increasing. SaWD are often highly relevant to the user's health and so could provide new insights into the causes and effects of cardiovascular diseases, and improve disease prediction, diagnosis and personalised treatment. Because these devices are already in widespread use, the costs of using such data in healthcare would be far lower than providing new devices or treatments. This makes it important to conduct research into the possible benefits that could result.

Despite its potential, SaWD alone have limited usefulness for health research unless it is also linked to data on the user's health. Without this, it is not possible to understand how SaWD changes in the presence of disease (to help diagnosis), in response to treatment (to measure the effects of treatment or identify people who benefit most), or how SaWD may predict development of future disease.

Our 2022 report highlighted the need for a UK-based large-scale research study of SaWD linked with participants' NHS data[1]. Without such a study, the potential health benefits of using SaWD will not be realised.

Although a research collection of SaWD linked with health data still does not exist, progress has been made that would enable it, particularly in access to and analysis of routinely collected healthcare data that could be linked with SaWD. The creation of Trusted Research Environments (TREs; highly secure computing environments that provide remote access to sensitive data for approved researchers to use in research) that link multiple, highly detailed NHS datasets has allowed large-scale research that would previously have been impossible. The next logical step is to link SaWD to such NHS datasets in

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[1] British Heart Foundation Data Science Centre. (2022). Workshop report – How can consumer wearables transform our understanding of cardiovascular disease? https://doi.org/10.5281/zenodo.5827260

a TRE. For legal and ethical reasons, this would require informed consent from each participant who would "opt-in" to such a research study.

The usefulness of a cohort of SaWD linked with healthcare data would be greatly limited if it is not diverse or representative of the population. Clinical tools developed on such data might not be effective in types of people not included in the original research. This means that a broad range of public and patients need to consent to have their SaWD collected, linked with their NHS data, and used in research. This would require them to understand what data will be collected, why it will be collected, and what it will be used for.

There is a trade-off between the desire of researchers to collect extensive and detailed SaWD and the acceptability of such research to potential participants who give consent to participate. We therefore asked the following questions:

- What SaWD do clinicians and researchers believe is most important for cardiovascular research?
- What SaWD do patients and the public feel is acceptable to collect in cardiovascular research?

Methods and results

We brought together a working group (JALM, RA-L, SC, AD, SH, LH-D, RS, MT, MT, SW and TC) composed of the study management team from the BHF Data Science Centre, clinicians and researchers from multiple institutions across the UK and Ireland and a UK-based patient advocate. The working group reviewed and confirmed the methodology (**Figure 1**).

Figure 1. Methodology.

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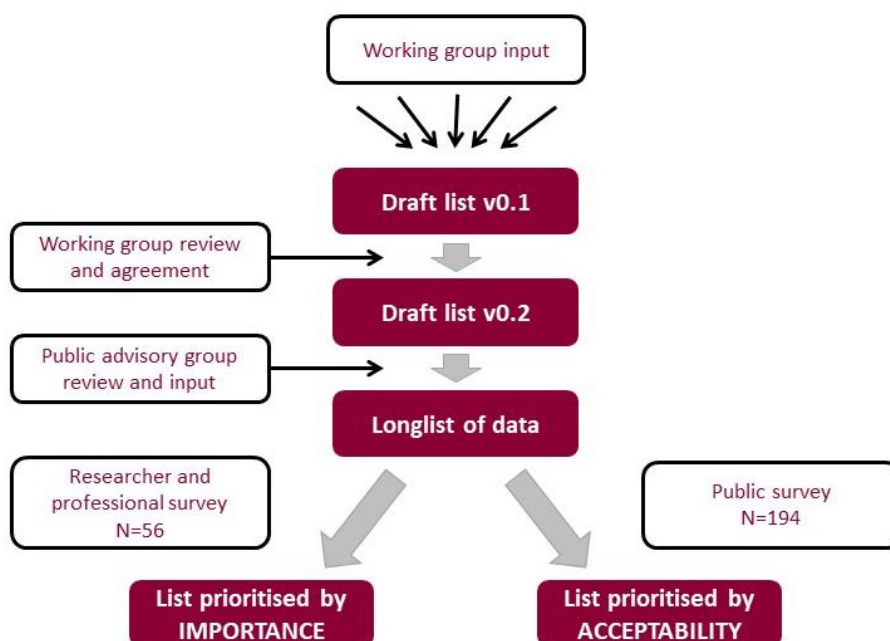
Developing a longlist of SaWD for cardiovascular research

The working group drafted an initial "longlist" of types of SaWD that could be considered for inclusion in a prospective research study (Draft list v0.1, **Appendix A**). This longlist was refined in a subsequent round of discussion (Draft list v0.2, **Appendix B**) which was then reviewed by members of the Public Advisory Group of the Smartphone and Wearable theme at the BHF Data Science Centre. The changes made to the list of data in response to input from the working group and Public Advisory Group are summarised in **Appendix C**.

This led to a final longlist of 33 measures. The longlist included: physiological measurements, measures of physical activity, GPS-derived measures including mobility and environment, self-reported measures of health and quality of life, and other measures deemed important for interpretation of the data (**Table 1**).

Several physiological measures (heart rate, oxygen saturation and respiratory rate) were included both as a continuous measure, enabling calculations of variability, and as a "snapshot", captured at a specified time. The working group agreed both measures should be included in the longlist as they provide different levels of information.

Each measure was categorised according to the likely method of capture. As method of capture affects both accuracy and the amount of user input required, this information was necessary to enable both the assessment of the importance of including each measurement and for members of the public to decide whether they would be in favour of sharing the measurement. Three categories of data capture were used:

- passive data which is automatically collected by device
- active data which the user manually enters into an app on a smartphone or wearable device
- GPS data which is calculated from GPS on a smartphone or wearable device.

Although GPS data is passive, the sensitivity of accessing such location data was felt to warrant separate consideration.

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Table 1. Longlist of SaWD for cardiovascular research.

Measurement	Category of data capture
Snapshot heart rate	Passive
Continuous heart rate	Passive
Snapshot oxygen saturation	Passive
Continuous oxygen saturation	Passive
Snapshot respiratory rate	Passive
Continuous respiratory rate	Passive
ECG parameters	Passive
Heart rhythm	Passive
Moderate intensity activity	Passive
Vigorous intensity activity	Passive
Steps per day	Passive
Walking cadence	Passive
Time spent sedentary per day	Passive
Sleep duration	Passive
Device carry time	Passive
Blood pressure	Active
Body weight	Active
Validated quality of life score	Active
Disease specific quality of life score	Active
Self-reported rating of anxiety and depression	Active
Self-reported rating of fatigue	Active
Self-reported rating of health	Active
Self-reported rating of life satisfaction	Active
Episodes of breathlessness, with time and duration	Active
Episodes of chest pain or discomfort, with time and duration	Active
Leg oedema	Active
Self-reported prescribed medication adherence	Active
Self-reported non-standard working hours e.g. shift pattern	Active
Average walking speed	GPS
Home location index of deprivation	GPS
Number of times out of home	GPS
Time away from home location	GPS
Total distance walked	GPS

Identification of SaWD of most importance to healthcare professionals and researchers
To identify which data is of highest priority for cardiovascular research, we conducted an online survey of researchers and healthcare professionals via SurveyMonkey. The survey (**Appendix D**) asked respondents to rate each measurement included in the longlist by importance and to suggest any additional measures that should be included. Respondents were told that:

> *We will create a dataset of personal monitoring data (linked to the person's NHS data) that:*
>
> - *Can be collected by a personal monitoring device such as a smartphone or wearable*
> - *Could enable discovery of links between smartphone/wearable data, current and future cardiovascular disease*
> - *Could address important research questions, such as; "how can smartphone and wearable data be used to predict future disease?" and "how can smartphone and wearable data improve earlier diagnosis of disease?"*
>
> *We're looking for researchers and healthcare professionals to help prioritise the personal monitoring data this dataset will include.*

The survey ran for 6 weeks from March to May 2023. Invitations to take part were distributed via emails to personal and professional networks and via the social media channels of HDR UK and the BHF Data Science Centre.

We received 56 completed surveys; 22% of respondents were healthcare professionals, 41% cardiovascular researchers, 39% data science researchers, and 25% personal monitoring researchers (totals exceed 100% as respondents could select more than one category).

Respondents were asked to rate each measure in **Table 1** on a five-point scale (*Very important=5, Important=4, Moderately important=3, Slightly important=2, Not important=1)*. **Table 2** shows a summary of the rating respondents gave to each measure.

Respondents were also asked to suggest additional measures important to include in any future study. We received 72 suggestions, of which 7 were already included in the list. Of the remaining 65, 39 were for data that were suggested more than once, listed in **Appendix E**. The most common suggestion was for continuous activity monitoring (a passive measure). Many of the other suggestions could be obtained from linked datasets or GPS including height, pollution, medical conditions/events, urban/rural location, weather/environment and altitude.

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Table 2. SaWD listed by mean importance from the survey of healthcare professionals and researchers.

Measurement	Mean importance rating +/- SD	Median	Interquartile range
Continuous heart rate	4.3 +/-0.7	4	1
Heart rhythm	4.3 +/-0.8	4	1
Moderate intensity activity	4.2 +/-0.9	4.5	1
Time spent sedentary per day	4.2 +/-0.9	4	1
Vigorous intensity activity	4.2 +/-0.9	4	1
Body weight	4.1 +/-0.7	4	1
Sleep duration	4 +/-1	4	1.75
Device carry time	4 +/-1.2	4	2
Total distance walked	4 +/-0.9	4	2
Episodes of chest pain or discomfort, with time and duration	4 +/-1	4	2
Steps per day	3.9 +/-1.2	4	2
Blood pressure	3.9 +/-1	4	2
ECG parameters	3.8 +/-1.1	4	2
Episodes of breathlessness, with time and duration	3.8 +/-1.1	4	2
Continuous oxygen saturation	3.7 +/-1.1	4	2
Validated quality of life score	3.6 +/-1	4	1
Self-reported rating of anxiety and depression	3.6 +/-0.8	4	1
Average walking speed	3.6 +/-1	4	1
Disease specific quality of life score	3.6 +/-0.9	4	1
Home location index of deprivation	3.6 +/-1.3	4	3
Self-reported rating of fatigue	3.6 +/-1	4	1
Snapshot heart rate	3.6 +/-1.2	4	2.25
Continuous respiratory rate	3.6 +/-1.2	4	1.25
Self-reported rating of health	3.5 +/-1.2	4	1.5
Walking cadence	3.5 +/-1.2	4	1
Self-reported prescribed medication adherence	3.5 +/-1.1	4	1
Self-reported non-standard working hours e.g. shift pattern	3.4 +/-1.1	3	1
Snapshot oxygen saturation	3.4 +/-1.2	3	2
Self-reported rating of life satisfaction	3.4 +/-1.1	4	1.25
Leg oedema	3.2 +/-1.1	3	2
Number of times out of home	3.2 +/-1.4	3	2
Snapshot respiratory rate	3.1 +/-1.1	3	2
Time away from home location	3 +/-1.3	3	2

Public views on acceptability of collection of each type of SaWD

We also surveyed patients and the public to understand their views on the acceptability of collecting SaWD data in the context of a research study.

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The survey was co-designed with a group of public representatives to ensure it was accessible, comprehensible, and in clear English, with careful consideration given to the clarity and inclusivity of all questions and response options. The survey asked respondents how they would feel about sharing each of the data in **Table 1** for research, to suggest any additional data they would include, and optional demographic questions to enable us to assess the representativeness of survey results.

To improve respondents' understanding, several of the names of the measures were changed in the public survey, for example "ECG parameters (such as PR duration, QRS duration, ST segment change)" was changed to "Measurement of heart electrical activity (called an ECG)". In addition, the public survey listed heart rate, respiratory rate (number of breathes you take per minute on average) and oxygen saturation (level of oxygen in the blood), rather than listing both continuous and snapshot measurements of each of these. The survey is included in **Appendix F**.

Respondents to the public survey were told that:

> *The British Heart Foundation Data Science Centre is working to improve the understanding, diagnosis and treatment of heart and/or circulatory disease by using personal monitoring data. Personal monitoring data comes from wearable devices like fitness watches and health-tracking mobile phone apps.*
>
> *We first want to find out what people think about sharing personal monitoring data for research and what types of personal monitoring data we should collect. This data would be linked to a person's health records to be used in research. This could allow us to ask important research questions, such as; "how can we use smartphone and wearable data to predict whether someone might develop heart disease?" and "how can smartphone and wearable data be used to improve earlier diagnosis of heart disease?".*

The dissemination of the survey aimed to reach a broad cross section of the UK. The survey was communicated via a news article[2], newsletters and shared across social media platforms, including Twitter/X, Facebook and LinkedIn, with a video[3] to support engagement. It was also shared by several organisations, including 65 local HealthWatch[4] via their communication platforms, with a wide geographical reach across England. We also provided all members of our Public Advisory Group with a communications toolkit to support dissemination via their networks.

The survey ran for 8 weeks over May and June 2023. A total of 194 respondents completed the survey. Of these (**Figure 2**) 58% were aged 55 or over, 62% were female, 6% were non-white. 33% had heart or circulatory disease, 32% had family members and/or friends with heart or circulatory disease, while 30% did not have heart or circulatory disease or family members and/or friends with heart or circulatory disease. The most common occupation of respondents was retired or other (39%), followed

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[2] https://www.hdruk.ac.uk/news/have-your-say-can-you-help-develop-a-smartphone-app-to-track-heart-health/

[3] https://www.youtube.com/watch?v=lXgWUsLa47M

[4] https://www.healthwatch.co.uk/

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by professionals (24%) managers or administrators (21%), with the remaining categories together contributing 15%.

Figure 2. Demographic characteristics of survey respondents, including: (a) Age, (b) Gender, (c) Ethnicity, (d) Whether respondents have or know someone who has heart or circulatory disease and (e) Occupation.
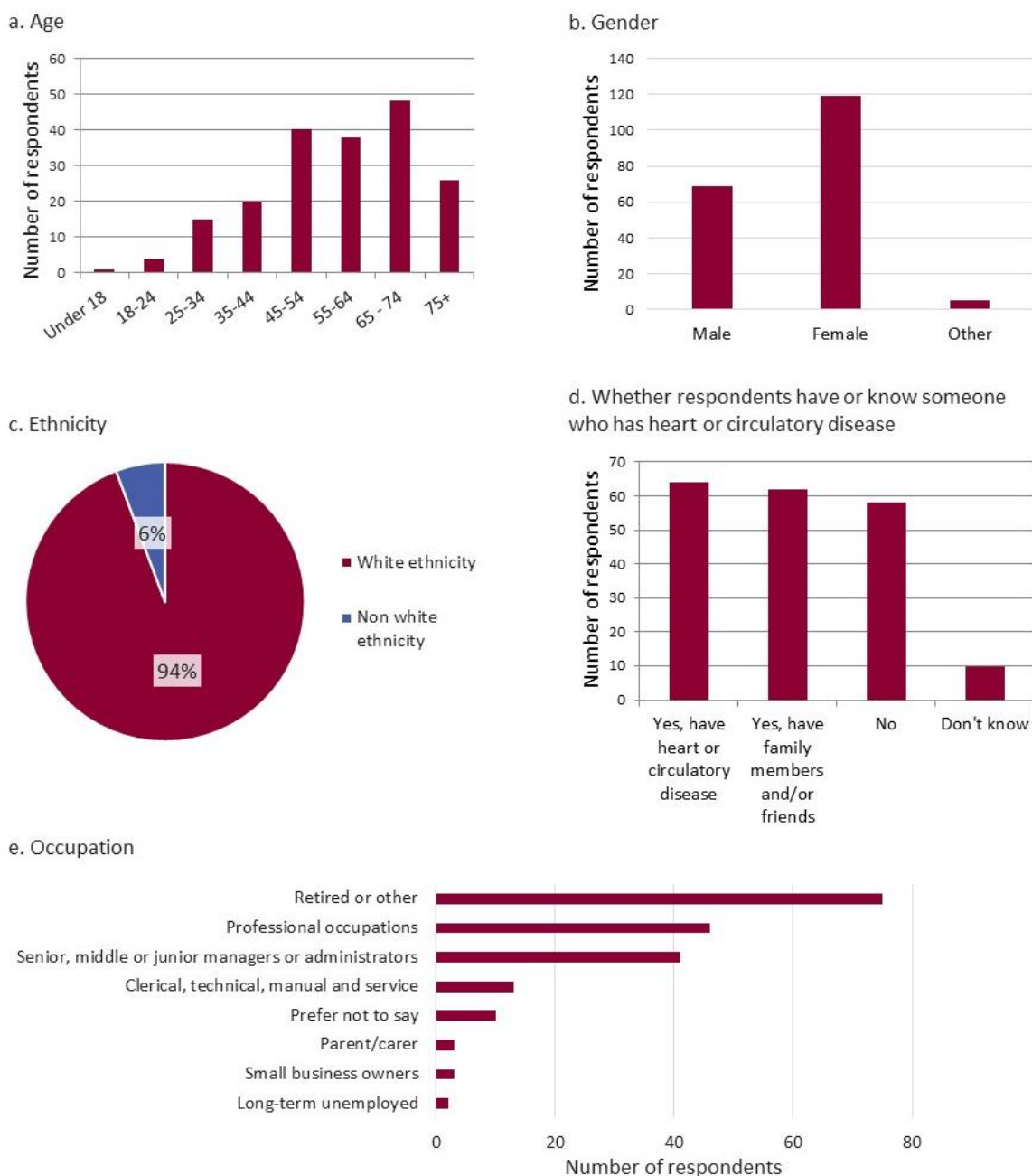
Respondents were asked how they would you feel about sharing each measure as part of a study that lasted several months for research, with the ability to rate each measure in **Table 1** as "in favour", "against", or "not sure". **Table 3** shows the % of public respondents that were in favour of sharing each measure.

Table 3. SaWD listed by the percentage of public survey respondents in favour of sharing each measure.

Measurement	% in favour of sharing
Snapshot heart rate	92%
Continuous heart rate	92%
Heart rhythm	90%
Snapshot respiratory rate	90%
Continuous respiratory rate	90%
Snapshot oxygen saturation	89%
Continuous oxygen saturation	89%
ECG parameters	86%
Steps per day	86%
Moderate intensity activity	85%
Time spent sedentary per day	85%
Average walking speed	85%
Walking cadence	84%
Total distance walked	83%
Vigorous intensity activity	82%
Blood pressure	82%
Sleep duration	82%
Device carry time	81%
Episodes of breathlessness, with time and duration	80%
Episodes of chest pain or discomfort, with time and duration	80%
Self-reported non-standard working hours e.g. shift pattern	78%
Self-reported prescribed medication adherence	77%
Self-reported rating of fatigue	76%
Leg oedema	73%
Body weight	73%
Self-reported rating of anxiety and depression	70%
Self-reported rating of health	70%
Validated quality of life score	69%
Disease specific quality of life score	69%
Self-reported rating of life satisfaction	67%
Number of times out of home	60%
Home location index of deprivation	56%
Time away from home location	55%

Public respondents were also asked to suggest additional measures that they felt should be collected. We received 112 suggestions, 23 of which were already included in the list. Of the remaining 89 suggestions, 66 were for data that were suggested more than once, listed in **Appendix G**. The most commonly suggested additional measure was diet, suggested by 16 respondents. Most of the other suggestions made by the public were for active data, including diet, alcohol use, blood glucose, free text comments and timing of medications.

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What data is both important for research and acceptable to collect?

Comparing the results of both surveys allows us to start to understand what types of SaWD would be of highest importance for researchers and most acceptable to possible participants to share. **Figure 3** shows the different measures placed in a grid that combines the importance that researchers placed on each measure with the acceptability of sharing by the public.

The measures that were of most importance to researchers (>3.68) AND that were most acceptable to the public (>74% in favour of sharing) are in the top right-hand corner of the grid, listed by importance. The most important and most acceptable measure was continuous heart rate.

Figure 3. The relationship between Importance and Acceptability for each measure. The lines of the grid are plotted at the mid-points of the range of each set of values (3.68 for importance and 74% for acceptability). Each measure is listed in order of importance within the relevant quadrant. SR = self-reported.
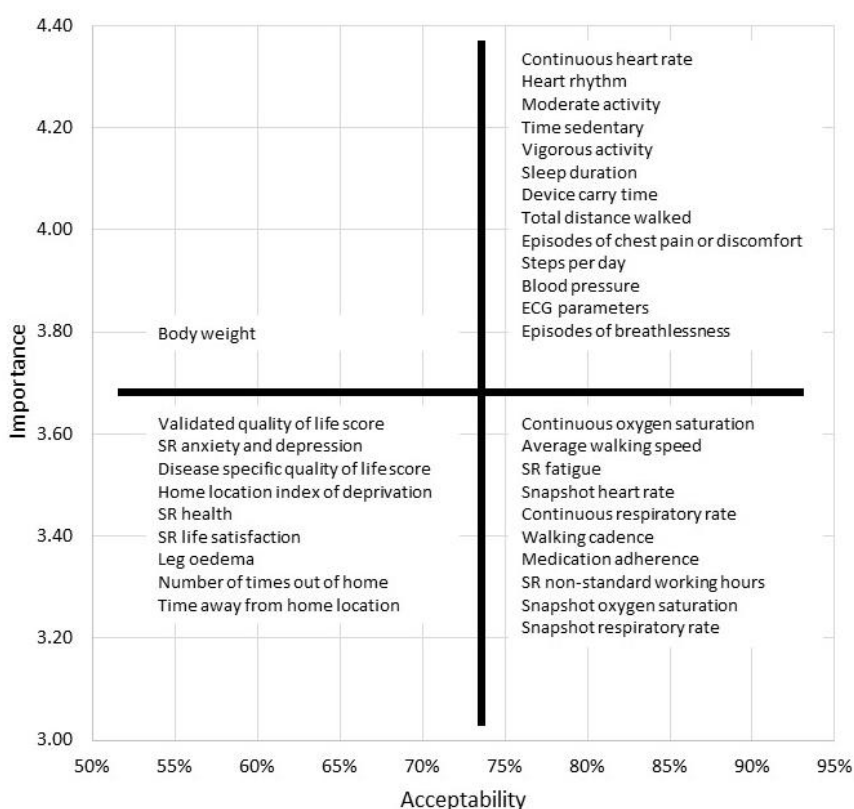
The 13 measures with the highest importance (>3.68) and acceptability (>74% in favour of sharing) were analysed to determine if different demographic groups feel differently about sharing these measures. For all demographic groups analysed (sex, age above/below 55, with or without heart or circulatory disease), the mean percent of respondents in favour of sharing all of these 13 measures combined was over 75%.

Discussion

Establishing a large-scale collection of SaWD linked with NHS data will require multi-million pound investment. It is therefore, essential that such a resource would be applicable to a broad range of cardiovascular research while being acceptable to potential study participants.

The data measures that researchers and healthcare professionals rated as of highest importance were predominantly passive and continuous (heart rate, activity, sleep) that are most accurately obtained using a wearable rather than a smartphone. Active (user inputted) data such as self-rated health, anxiety, depression, and quality of life were seen on average as somewhat less important. This is of interest as we might have expected that self-rated health would be seen as a more meaningful aspect of health than passively sensed data which cannot directly describe how a person "feels". It is possible that researchers and healthcare professionals prioritised data that can only be measured by wearables or smartphones, therefore making the most of the unique advantages of these devices, rather than data that could be obtained in other ways (such as face-to-face visits or online or paper-based questionnaires). It would be useful to explore this more as active data, however obtained, would be required to understand the relationships between passive data and subjectively-rated health, the improvement of which is often a goal of healthcare.

The public survey showed a similar preference for passively-sensed data (requiring a wearable) compared with active data from a smartphone. It is possible that this reflects the convenience of passive data capture, compared with the inevitable requirement to commit time to completion of questionnaires and other inputs. Future work should explore how often and for how long potential study participants would be willing to give up their time to input active data.

An alternative reason for the professional and public groups alike to have prioritised passive data, is that many of these measures (such as heart rate) are widely known to be associated with cardiovascular health and disease. However, continuously measuring such data over years, compared with previous approaches which used sporadic measurement at rest, may show stronger associations with risk of disease, and detect disease earlier.

Some of the measures on the original longlist could be derived from other sources, including the NHS medical record. Examples of this are blood pressure, and home postcode to allow identification of home location index of deprivation. Where such data can be obtained from other sources without compromising accuracy, there is little reason to commit resource to its collection from smartphones and wearables. However, as technology advances, wearable blood pressure monitors may provide more regular and more reliable data than sporadic clinical measurement.

The fact that we did not identify any additional suggestions at a high level from researchers and professionals leads us to conclude that we have identified the SaWD with the most utility for cardiovascular research. Several additional data were suggested by the public, most notably diet. Many of these additional measures were active and had been considered in discussions during the creation of the longlist. They were not included in the original longlist due to their collection being perceived to place a high burden on participants and high levels of variability in accuracy. However, they should be considered as potential additional data to explore in future studies, including determining the proportion of the public in favour of sharing.

A possible limitation of this study is potential bias or lack of representativeness in the public surveyed. The survey was carried out online, which will have limited respondents to members of the public with internet access. However, given that participants of such a study would need to be users of a smartphone at minimal, this should not unduly bias respondents compared to the population of potential study participants. Only 6% of respondents reported as non-white ethnicity, compared to 18%[5] of the English and Welsh population. We would suggest that a future study engages with patients and public representative of the UK population, ensuring that non-white ethnicities and other under-

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[5] https://www.ethnicity-facts-figures.service.gov.uk/

represented groups are included. This will be particularly important in ensuring recruitment strategies and study materials are accessible and do not unfairly target or disadvantage particular groups.

While we have defined a list of SaWD with high levels of utility and acceptance, challenges remain before the creation of such a dataset with linkage to health data can be realised. The highest ranked measure for both professionals and the public was continuous heart rate. Linkage of this (and other continuous measures) represents a methodological and analytical challenge, particularly at large scale. There are unresolved questions about the extent by which continuous measures should be processed prior to linkage, to reduce storage and computational demand. Such issues need to be addressed before building the technical infrastructure required to securely store and analyse the data collected.

Our findings show a clear preference for data that is most accurately and easily collected using a wearable. However, such devices are far less prevalent than smartphones, meaning that research that relies on ownership would be biased towards recruiting more affluent participants. A future study should consider providing devices to at least a proportion of participants. Furthermore, the wide array of different wearable devices raises challenges of interoperability if a study relies on existing device ownership rather than provision of a single type of device. This requires basic research into the comparability of data from different devices and the establishment of data standards to allow them to be integrated within the same study.

The prioritised list of SaWD defined in this report can serve as a starting point for the creation of a large-scale dataset that can be linked to health data. These data can also serve as a focus for pilot studies to explore and develop strategies to address the methodological, analytical and interoperability challenges involved. In addition, our work involving and consulting patients and the public is a necessary step towards obtaining ethical approval for studies in this area from the Health Research Authority (HRA).

Our next steps will be to define the infrastructure, data standards, analytics and clinical study design required to achieve our goal of a large-scale collection of SaWD linked with NHS data. We believe a realistic first phase would be to recruit 10,000 participants to test the approaches used and to support initial research studies whose findings would justify further scale-up and investment.

Acknowledgements

Conflicts of interest

All authors declare that they have no conflicts of interest.

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Appendices

Appendix A – Draft list v0.1

DATA CATEGORY	PROPOSED MEASUREMENT	HOW MEASURED	FREQUENCY OF MEASUREMENT
ACTIVITY	STEPS/D MINUTES OF ACTIVITY/D STAIR USE/D SEDENTARY TIME/D WALKING CADENCE (STEPS/MIN)	ACCELEROMETRY (PHONE/WEARABLE)	NEAR-CONTINUOUS
	AVE WALKING SPEED DISTANCE WALKED/D	GPS (PHONE/WEARABLE)	NEAR-CONTINUOUS
MOBILITY	NUMBER OF TIMES LEFT HOME TIME AWAY FROM HOME/D MOTOR VEHICLE TRIPS/D TIME IN MOTOR VEHICLE/D RADIUS FROM HOME/D	GPS (PHONE/WEARABLE)	NEAR-CONTINUOUS
PHYSIOLOGY	RESTING HEART RATE AWAKE AVERAGE HR SLEEPING AVERAGE HR MAX HR HR RECOVERY	PPG/ECG (WEARABLE)	NEAR-CONTINUOUS
	BLOOD PRESSURE	CUFF/CUFFLESS DEVICE	USER-ACTIVATED: DAILY-MONTHLY
	O2 SATURATION RESPIRATORY RATE	PHOTOPLETHYSMOGRAPHY (PPG) SENSOR (WEARABLE)	NEAR-CONTINUOUS
	SINGLE-LEAD ECG	WEARABLE	USER-ACTIVATED
	SLEEP HRS/D	ACCELEROMETRY (WEARABLE)	DAILY
ENVIRONMENT	SOCIO-ECONOMIC AIR TEMPERATURE WEATHER AIR QUALITY NOISE LEVELS	GPS (PHONE/WEARABLE)	NEAR-CONTINUOUS
DEVICE DATA	WEAR/CARRY TIME/D CHARGING FREQUENCY	DEVICE DATA	NEAR-CONTINUOUS
SYMPTOM RECORDING	ONSET/OFFSET ALL PARAMETERS ABOVE AT ONSET	USER INPUT (e.g. in APP user select symptom from list and enter onset/offset, with option for free text entry of symptom not in list)	USER-ACTIVATED

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DATA CATEGORY	PROPOSED MEASUREMENT	HOW MEASURED	FREQUENCY OF MEASUREMENT
QUALITY OF LIFE	"Overall, how satisfied are you with your life nowadays? (0-10)"	USER INPUT	PERIODIC
SELF-RATED HEALTH	"Rate your health today on a scale 0-100" *(0 is the worst you can imagine, 100 is the best you can imagine)*	USER INPUT	PERIODIC

Appendix B – Draft list v0.2

Category	Measurement	Method of collection (automated/manual entry/GPS)
Measures of Symptoms	Episodes of breathlessness (n/d)	Manual entry
	Episodes of chest pain (n/d)	Manual entry
	Duration of symptoms (min per episode) *Note - this would be collected for each symptom reported*	Manual entry
	Time of symptoms onset (HH:MM) *Note - this would be collected for each symptom reported*	Manual entry
Measures of Quality of Life/ Self Rated Health	Overall, how satisfied are you with your life this week? (0-10)	Manual entry
	Rate your health this week on a scale 0-100	Manual entry
	Validated quality of life score e.g. EXTENDED HRQoL e.g. EQ-5D-5L	Manual entry
	Disease specific quality of life score (ie emPHasis-10)	Manual entry
Measures of Physiology	Body weight (kg)	Manual entry
	Blood Pressure (mmHg)	Manual entry
	Resting Heart Rate (beats per min)	Automated
	Sleep duration (hours/day)	Automated
	Heart Rhythm (categorical: normal, AF, atrial flutter, ectopics, need to clarify)	Automated
	Average Respiratory Rate (per min)	Automated
	Awake Average Heart Rate (beats per min)	Automated
	Max Heart Rate (beats per min)	Automated
	Average Oxygen Saturation (%) per day	Automated
	Heart Rate Recovery	Automated
	Sleeping Average Heart Rate (beats per min)	Automated
	Average Nocturnal Oxygen Saturation (%) per day	Automated
	ECG parameters (PR duration, QRS duration)	Automated
	Lowest Oxygen Saturation (%) per day	Automated
	Leg Oedema (mid-calf circumference mm)	Manual entry
Measures of Mobility	Number of times out of home location (n/d)	GPS
	Time away from home location (min/d)	GPS
Measures of Environment	Home location index of deprivation (deprivation quintile)	GPS
Measures of Device Use	Device carry time (minutes/d)	Automated
Measures of Activity	Steps per day (total)	Automated
	Time spent sedentary per day	Automated
	Minutes of moderate intensity activity per day	Automated
	Minutes of vigorous intensity activity per day	Automated

Category	Measurement	Method of collection (automated/manual entry/GPS)
	Average walking speed (meters per min)	GPS
	Total distance walked (meters per day)	GPS
	Walking cadence (steps per min)	Automated

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Appendix C - Summary of changes made to the list of data in response to input from the working group and Public Advisory Group (PAG).

Key - Field highlighting:

Green = Measurement included in list version

Orange = Measurement included in list version to some extent, but changes made

Summary of change	Measurement	List version included in		
		v0.1	v0.2	Longlist
Included throughout longlist creation process	ECG parameters	🟩	🟩	🟩
	Steps per day	🟩	🟩	🟩
	Walking cadence	🟩	🟩	🟩
	Time spent sedentary per day	🟩	🟩	🟩
	Sleep duration	🟩	🟩	🟩
	Device carry time	🟩	🟩	🟩
	Self-reported rating of health	🟩	🟩	🟩
	Self-reported rating of life satisfaction	🟩	🟩	🟩
	Average walking speed	🟩	🟩	🟩
	Number of times out of home	🟩	🟩	🟩
	Time away from home location	🟩	🟩	🟩
	Total distance walked	🟩	🟩	🟩
	Blood pressure	🟩	🟩	🟩
Frequency of capture or time-span of calculation changed	Snapshot heart rate measurement	🟧	🟧	🟩
	Continuous heart rate measurement	🟧	🟧	🟩
	Snapshot oxygen saturation measurement	🟧	🟧	🟩
	Continuous oxygen saturation measurement	🟧	🟧	🟩
	Snapshot respiratory rate measurement	🟧	🟧	🟩
	Continuous respiratory rate measurement	🟧	🟧	🟩
	Moderate intensity activity	🟧	🟩	🟩
	Vigorous intensity activity	🟧	🟩	🟩
Added following working group review	Heart rhythm		🟩	🟩
	Body weight		🟩	🟩
	Validated quality of life score		🟩	🟩
	Disease specific quality of life score		🟩	🟩
	Episodes of breathlessness, with time and duration		🟩	🟩
	Episodes of chest pain or discomfort, with time and duration		🟩	🟩
	Leg oedema		🟩	🟩
	Home location index of deprivation		🟩	🟩
Added following PAG review	Self-reported rating of anxiety and depression			🟩
	Self-reported rating of fatigue			🟩
	Self-reported prescribed medication adherence			🟩
	Self-reported non-standard working hours e.g. shift pattern			🟩

Summary of change	Measurement	List version included in		
		v0.1	v0.2	Longlist
Removed following working group review	Charging frequency			
	Stair use			
	Motor vehicle trips			
	Time in motor vehicle			
	Radius from home			
	Socioeconomic			
	Air temperature			
	Weather			
	Air quality			
	Noise levels			

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Appendix D – Researcher and healthcare professional survey

Prioritising personal monitoring data for research to improve understanding of cardiovascular disease

Personal monitoring data is information collected by wearable devices like fitness watches and health-tracking phone apps. The British Heart Foundation Data Science Centre aims to improve understanding of cardiovascular disease using personal monitoring data.

We will create a dataset of personal monitoring data (linked to the person's NHS data) that:
- **Can be collected by a personal monitoring device such as a smartphone or wearable**
- **Could enable discovery of links between smartphone/wearable data and current and future cardiovascular disease**
- **Could address important research questions, such as; "how can smartphones and wearable data be used to predict future disease?" and "how can smartphones and wearable data improve earlier diagnosis of disease?"**

We're looking for researchers and healthcare professionals to help prioritise the personal monitoring data this dataset will include.

Please complete this survey and have your say. It should take no more than 10 minutes.

Prioritising personal monitoring data for research to improve understanding of cardiovascular disease

Prioritising personal monitoring data

* 1. How important is it to include these passive data, which are automatically collected by devices? Please rate.

	Very important	Important	Moderately important	Slightly important	Not important	Not able to rate
A snapshot heart rate measurement (when prompted)	○	○	○	○	○	○
Continuous heart rate measurement (allowing calculation of specific measures e.g. max/min and heart rate recovery)	○	○	○	○	○	○
A snapshot oxygen saturation measurement (when prompted)	○	○	○	○	○	○
Continuous oxygen saturation measurement (allowing calculation of specific measures e.g. max/min)	○	○	○	○	○	○
A snapshot respiratory rate measurement (when prompted)	○	○	○	○	○	○
Continuous respiratory rate measurement (allowing calculation of specific measures e.g. max/min)	○	○	○	○	○	○
ECG parameters (such as PR duration, QRS duration, ST segment change)	○	○	○	○	○	○
Heart rhythm (normal or irregular - AF, atrial flutter, ectopics)	○	○	○	○	○	○
Moderate intensity activity (min per day)	○	○	○	○	○	○

Vigorous intensity activity (min per day)	○	○	○	○	○	○
Steps per day (total)	○	○	○	○	○	○
Walking cadence (steps per min)	○	○	○	○	○	○
Time spent sedentary per day (min)	○	○	○	○	○	○
Sleep duration (hours per day)	○	○	○	○	○	○
Device carry time (min per day)	○	○	○	○	○	○

2. Is there any additional data automatically collected by phone/wearable that is important to include?

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* 3. How important is it to include these active or user-generated data, which are manually entered into an app on a phone/wearable? Please rate.

Note – The frequency of collection of each will vary depending on the research study.

	Very important	Important	Moderately important	Slightly important	Not important	Not able to rate
Blood pressure (mmHg)	○	○	○	○	○	○
Body weight (kg)	○	○	○	○	○	○
Validated quality of life score (calculated by answering a series of questions in the app)	○	○	○	○	○	○
Disease specific quality of life score (calculated by answering a series of questions in the app)	○	○	○	○	○	○
Self-entered rating of anxiety and depression,	○	○	○	○	○	○
Self-reported rating of fatigue	○	○	○	○	○	○
Self-reported rating of health (0-100)	○	○	○	○	○	○
Self-reported rating of life satisfaction, (rate 0-10)	○	○	○	○	○	○
Episodes of breathlessness, with time and duration of symptoms (when this occurs)	○	○	○	○	○	○
Episodes of chest pain or discomfort, with time and duration of symptoms (when this occurs)	○	○	○	○	○	○
Leg oedema (midcalf circumference measured by tape measure in mm)	○	○	○	○	○	○
Self-reported prescribed medication adherence	○	○	○	○	○	○
Self-reported non-standard working hours e.g. shift pattern	○	○	○	○	○	○

4. Is there any additional manually entered data that is important to include?

* 5. How important is it to include these data calculated from GPS on a phone/wearable? Please rate.

	Yes, important	Important	Moderately important	Slightly important	Not important	Not able to rate
Average walking speed (metres per min)	○	○	○	○	○	○
Home location index of deprivation (deprivation quintile)	○	○	○	○	○	○
Number of times out of home (number per day)	○	○	○	○	○	○
Time away from home location (min per day)	○	○	○	○	○	○
Total distance walked (metres per day)	○	○	○	○	○	○
Time spent in motor vehicles (min per day)	○	○	○	○	○	○

6. Is there any additional data that can be calculated from GPS data that is important to include?

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Using this personal monitoring dataset

7. If this dataset of personal monitoring data was available linked to health data for cardiovascular research, how would you want to use this?

8. What in your opinion is the most important research question that such a dataset could be used to address?

9. Any additional comments?

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About you

* 10. Which of the following categories describe your role?
Please select all categories that apply.

- [ ] Member of the public/patient
- [ ] Researcher (cardiovascular disease)
- [ ] Researcher (personal monitoring)
- [ ] Researcher (data science and/or computer science)
- [ ] Researcher (other)
- [ ] Healthcare professional (including NHS)
- [ ] Research funder
- [ ] Company representative
- [ ] Other (please specify)

11. Please enter your name and email address if you would like to be updated on the results of this survey

Name

Email Address

Prioritising personal monitoring data for research to improve understanding of cardiovascular disease

Thank you for taking the time to complete this survey!

To find out more about the BHF Data Science Centre please visit our webpage

To contact us email bhfdsc@hdruk.ac.uk

Appendix E – Additional data from researcher and healthcare professional survey that was suggested more than once

Suggestion	Number of times suggested	Category of data capture
Continuous activity monitoring	5	Passive
Height	5	Linked data
Pollution	4	GPS
Medical conditions/events	3	Linked data
Urban/rural location	3	GPS
Weather/environment	3	GPS
Altitude	2	GPS
Ambient temperature	2	Passive
Diet	2	Active
Screen time	2	Passive
Self-reported fitness	2	Active
Sleep disturbances	2	Passive
Smoking status	2	Linked data
Self-reported social contact	2	Active
Total number of suggestions	39	

Appendix F – Public survey

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Let us know what you think about sharing data from smartphone apps or smartwatches

We are seeking public input to help design a new app that could better spot how data collected from smartphones and smartwatches varies with changing heart health.

At the British Heart Foundation Data Science Centre, we are working to improve the understanding, diagnosis and treatment of heart and circulatory disease through smartphones and smartwatches. This information is a realistic reflection of our activity and health because it is gathered over long periods in home settings, complementing snapshots recorded in hospitals or GP practices.

We want to find out what people think about sharing data from smartphone apps and smartwatches for research and what types of data an app should collect. This data could be linked to a person's health records to be used in research and could allow us to ask important research questions, such as; how smartphone and smartwatch data could predict whether someone might develop heart disease, or how smartphone and smartwatch data might improve earlier diagnosis.

We appreciate your help in designing an app that is safe, secure and collects meaningful information.

This survey will take approximately 10 minutes to complete.

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Let us know what you think about sharing data from smartphone apps or smartwatches

* 1. Which of these factors would make you willing to download and install an app on your smartphone to collect and share smartphone or smartwatch data for research?

Please list in order of importance, with "1" being most important.

- Recommendation by a medical professional
- The app having the BHF Data Science Centre logo
- The app having the logo of UK Universities involved in the project
- Reading about the app in a news article or blog
- Seeing the app advertised on social media e.g. Twitter or Facebook
- Knowing that the app had been developed with patients/members of the public

2. Is there anything else that would make you likely to download and install an app on your smartphone to collect and share smartphone or smartwatch data?

3. Do you have any concerns about downloading and installing an app on your smartphone to collect and share smartphone or smartwatch data?

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* 4. **Which of these factors would influence your decision on whether you were happy to enter your NHS number (CHI number in Scotland) or other identifying information into the app to enable linkage of your NHS record to this smartphone or smartwatch data?**

Please list in order of importance, with "1" being most important.

≡ [⬍]   Knowing where to find my NHS number

≡ [⬍]   Knowing why I was being asked to provide my NHS number

≡ [⬍]   Knowing how my data will be kept safe

≡ [⬍]   Knowing how my identity will be kept anonymous

≡ [⬍]   Knowing how my data will be anonymised

≡ [⬍]   Knowing how my smartphone or smartwatch data will be linked to my NHS record

≡ [⬍]   Knowing why my smartphone or smartwatch data needs to be linked to my NHS record

5. **What else would you want to know before entering your NHS number (CHI number in Scotland) or other identifying information?**

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6. **Would you have any concerns?**

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* 7. **Which of this information would you want to know before deciding to share smartphone or smartwatch data collected over several months and linked to your NHS record to be used in heart and circulatory disease research?**

Please list in order of importance, with "1" being most important.

≡ [⬍]   Why I am being asked to share my data

≡ [⬍]   What research my data will be used for

≡ [⬍]   Who will be able to see my data

≡ [⬍]   How will my data be kept secure

≡ [⬍]   How I can stop sharing my data

≡ [⬍]   Whether I will be involved in the discussions about how my data is used

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8. **What else would you want to know about sharing this information?**

9. **Would you have any concerns?**

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Let us know what you think about sharing data from smartphone apps or smartwatches

Help us decide what data we should collect from smartphones or smartwatches

Data automatically collected by your smartphone/smartwatch

This question asks your opinions about data that could be collected by an app on your smartphone. Some of this data might also be collected by a smartwatch or wearable (like a Fitbit or Apple watch), if you have one. The data could be collected without you having to do anything other than wear or carry the device.

Please note - we are still want your views, even if you don't have any of these devices.

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* 10. **How would you feel about sharing the data listed below as part of a study
that lasted several months for research?**

	In favour	Against	Not sure
Level of oxygen in your blood, measured by a camera on your smartphone or smartwatch	○	○	○
Number of breathes you take per minute on average	○	○	○
Heart rate	○	○	○
Amount of time the device (smartphone or smartwatch) is carried/worn per day	○	○	○
Measurement of heart electrical activity (called an ECG)	○	○	○
Whether your heart rhythm is normal or irregular, as detected by your smartphone or smartwatch (Irregular heart rhythm)	○	○	○
Amount (in minutes) of moderate physical activity per day (Moderate exercise)	○	○	○
Amount (in minutes) of intense physical activity per day (Intense exercise)	○	○	○
Time spent asleep per day	○	○	○
Steps per day (total)	○	○	○
Time spent sitting per day	○	○	○
Walking speed	○	○	○

Any other data you would suggest?

[   ]

11. Please enter any additional comments.

[   ]

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Let us know what you think about sharing data from smartphone apps or smartwatches

Data self-entered into an app on your smartphone or smartwatch

This question asks your opinions about information that you could enter yourself into an app on your smartphone. Some of this information might come from a separate device like a blood pressure monitor or weighing scales. If you have this type of device you would need to manually enter the measurements such as your blood pressure or weight, into the app on your smartphone.

* 12. How would you feel about sharing the data listed below as part of a study that lasted several months for research?

	In favour	Against	Not sure
Blood Pressure (entered weekly and if you feel unwell)	○	○	○
Body weight (entered no more then weekly)	○	○	○
A record of any times you experience shortness of breath, with time and duration of symptoms (entered whenever this occurs)	○	○	○
A record of any times you experience chest pain or discomfort, with time and duration of symptoms (entered whenever this occurs)	○	○	○
Swelling of legs, measured by a tape measure around the middle of your calf (entered whenever this occurs)	○	○	○
Rate how satisfied you are with your life, with a score 0-10 (entered weekly)	○	○	○
Rate your health, with a score 0-100 (entered weekly)	○	○	○
Complete a series of questions to assess your quality of life	○	○	○

(completed monthly)			
Rate your fatigue level this week, with a score 0-10 (entered weekly)	○	○	○
Complete a series of questions to assess your level of anxiety and depression (completed monthly)	○	○	○
Answer a question to help understand how often you take any medication that is prescribed to you (completed weekly)	○	○	○
Answer a question to help understand whether you work non-standard hours e.g. shifts (completed once at start of study with ability to update)	○	○	○

Any other data you would suggest?

[   ]

13. Please enter any additional comments.

[   ]

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Let us know what you think about sharing data from smartphone apps or smartwatches

Data calculated from GPS data from your smartphone or smartwatch

The questions on this page ask your opinions about data that can be generated using GPS on your smartphone or smartwatch. This information is calculated based on your location data, but the researcher or clinician will not have access to your actual location information. Instead, they will only see the final measurement calculated using this data such as total distance walked in metres per day.

* 14. How would you feel about sharing the data listed below as part of a study that lasted several months for research?

	In favour	Against	Not sure
Average walking speed	○	○	○
Total distance walked per day	○	○	○
A standardised measure of the income levels in your area	○	○	○
How many times you are outside of your home each day	○	○	○
Total amount of time you spend away from your home location each day	○	○	○

Any other data you would suggest?

15. Please enter any additional comments.

Let us know what you think about sharing data from smartphone apps or smartwatches

About you

We want to ensure that we collect input from a wide range of people and understand what is important to them. The following questions will help us achieve this.

Please note - any information you provide will be kept anonymous and you do not need to complete any of these questions if you would rather not share any of this information.

16. **Which of the following categories best describe your role?**
Please select all categories that apply.

- [ ] Member of the public/patient
- [ ] Researcher (cardiovascular disease)
- [ ] Researcher (data science and/or computer science)
- [ ] Researcher (other)
- [ ] Healthcare professional (including NHS)
- [ ] Research funder
- [ ] Company representative (healthtech or smartphone/smartwatch technology)
- [ ] Other (please specify)

[   ]

17. **Do you or someone you know have heart or circulatory disease?**
(Please select all that apply)

- ( ) Yes, I have heart or circulatory disease
- ( ) Yes, I have family members and/or friends that have heart or circulatory disease
- ( ) No
- ( ) Don't know

18. **What is your age?**

◯ Under 18

◯ 18-24

◯ 25-34

◯ 35-44

◯ 45-54

◯ 55-64

◯ 65 - 74

◯ 75+

19. **How would you describe your gender?**

◯ Male

◯ Female

◯ Nonbinary

◯ Prefer not to say

◯ Other (please specify)

[   ]

20. **Is your gender identity the same as the sex you were assigned at birth?**

◯ Yes

◯ No

◯ Prefer not to say

◯ Not known

21. **Which of these most closely represents your main occupation?**

○ Modern professional and traditional professional occupations
such as: teacher, nurse, physiotherapist, social worker, musician, police officer (sergeant or above), software designer, accountant, solicitor, medical practitioner, scientist, civil or mechanical engineer

○ Senior, middle or junior managers or administrators
such as: finance manager, chief executive, large business owner, office manager, retail manager, bank manager, restaurant manager, warehouse manager

○ Clerical and intermediate occupations
such as: secretary, personal assistant, call centre agent, clerical worker, nursery nurse

○ Technical and craft occupations
such as: motor mechanic, plumber, printer, electrician, gardener, train driver

○ Routine, semi-routine manual and service occupations
such as: postal worker, machine operative, security guard, caretaker, farm worker, catering assistant, sales assistant, HGV driver, cleaner, porter, packer, labourer, waiter or waitress, bar staff

○ Long-term unemployed
claimed Jobseeker's Allowance or earlier unemployment benefit for more than a year

○ Small business owners who employed less than 25 people
such as: corner shop owners, small plumbing companies, retail shop owner, single restaurant or cafe owner, taxi owner, garage owner

○ Parent/carer

○ Other
such as: retired, this question does not apply to me, I don't know

○ Prefer not to say

22. **Which of these most closely represents the occupation of your main household earner when you were aged about 14?**

○ Modern professional and traditional professional occupations
such as: teacher, nurse, physiotherapist, social worker, musician, police officer (sergeant or above), software designer, accountant, solicitor, medical practitioner, scientist, civil or mechanical engineer

○ Senior, middle or junior managers or administrators
such as: finance manager, chief executive, large business owner, office manager, retail manager, bank manager, restaurant manager, warehouse manager

○ Clerical and intermediate occupations
such as: secretary, personal assistant, call centre agent, clerical worker, nursery nurse

○ Technical and craft occupations
such as: motor mechanic, plumber, printer, electrician, gardener, train driver

○ Routine, semi-routine manual and service occupations
such as: postal worker, machine operative, security guard, caretaker, farm worker, catering assistant, sales assistant, HGV driver, cleaner, porter, packer, labourer, waiter or waitress, bar staff

○ Long-term unemployed
claimed Jobseeker's Allowance or earlier unemployment benefit for more than a year

○ Small business owners who employed less than 25 people
such as: corner shop owners, small plumbing companies, retail shop owner, single restaurant or cafe owner, taxi owner, garage owner

○ Other
such as: retired, this question does not apply to me, I don't know

○ Prefer not to say

40

23. **How would you describe your ethnic origin?**

○ Asian or Asian British – Indian

○ Asian or Asian British – Pakistani

○ Asian or Asian British - Bangladeshi

○ Asian or Asian British - Chinese

○ Asian or Asian British - Any other Asian background

○ Black, Black British, Caribbean or African - Caribbean

○ Black, Black British, Caribbean or African - African

○ Black, Black British, Caribbean or African - Any other Black, Black British, or Caribbean background

○ Mixed or multiple ethnic groups - White and Black Caribbean

○ Mixed or multiple ethnic groups - White and Black African

○ Mixed or multiple ethnic groups - White and Asian

○ Mixed or multiple ethnic groups - Any other Mixed or multiple ethnic background

○ White - English, Welsh, Scottish, Northern Irish or British

○ White - Irish

○ White - Gypsy or Irish Traveller

○ White - Roma

○ White - Any other White background

○ Other ethnic group - Arab

○ Other ethnic group - Any other ethnic group

Let us know what you think about sharing data from smartphone apps or smartwatches

Thank you for taking the time to complete this survey.

Your input will help design the app and decide the best information to collect.

To find out more about the BHF Data Science Centre please visit our webpage

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Appendix G – Additional data from public survey that was suggested more than once

Suggestion	Number of times suggested	Category of data capture
Diet	16	Active
Alcohol use	5	Active
Blood glucose	4	Active
Free text comments	3	Active
Gait	3	Passive
Timing of medications	3	Active
Type of activity	2	Active
Behaviour	2	Active
Blood cortisone	2	Active
Eye pressure	2	Active
Family circumstances	2	Active
Medical conditions/events	2	Linked data
Medication	2	Linked data
Occupation	2	Active
Personal circumstances	2	Active
Pollution	2	GPS
Self-reported health conditions/illness	2	Active
Sleep disturbances	2	Passive
Smoking status	2	Linked data
Social contact	2	Active
Ambient temperature	2	GPS
VO2	2	Active
Total number of suggestions	66	