

MAY 28th 2021

DATA DIALOGUES

Exploring possible, trusted futures for shared health data across Scotland.



Shift

**DARTINGTON
SERVICE
DESIGN LAB**

nesta

MadeByPlay

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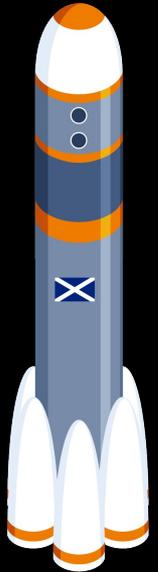
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PROJECT BACKGROUND



PROJECT BACKGROUND

IT'S WIDELY ACCEPTED THAT EFFECTIVE USE OF SHARED HEALTH AND CARE DATA CAN IMPROVE INDIVIDUALS' LIVES AND CREATE A MORE EFFECTIVE, EFFICIENT HEALTH CARE SYSTEM.

Commissioned by the Scottish Government as part of the Data Dialogues research initiative, Shift worked with Nesta to explore possible, trusted futures for shared health data across Scotland. It's widely accepted that effective use of shared health and care data can improve individuals' lives and create a more effective, efficient health care system. The public typically support sharing patient data within the public health system, however they are largely distrustful of sharing data with commercial organisations (Ford et al, 2017). Scotland's strategic aim for health and social care is to provide high quality services, with a focus on prevention, early intervention and supported self-management.

To achieve this, a vision for shared health data must go beyond what sits in health records and integrate data that sits across many domains of the lives of the public.

Led by MadeByPlay (a venture within Shift that fuses creativity, play and research rigour) and Dartington Service Design Lab - the intention of this project was to explore a range of possible, trusted futures in a way that moves beyond traditional research methods and towards more participatory discourse. Our intention was to create spaces where power differentials are overridden and people are empowered to critically reflect and imagine together, from the perspective of the individual, the community, and society as a whole.

SECTION 02:

SCOTLAND ON MARS



ABOUT THE GAME

IF YOU WERE MINISTER OF
THE **MARS HEALTH SERVICE**,
RESPONSIBLE FOR SETTING UP
THE HEALTHCARE SYSTEMS FOR
A NEW CIVILISATION, WHAT
CHOICES WOULD YOU MAKE?



THIS WAS THE CORE QUESTION WE SET OUT TO EXPLORE WITH 16-18 YEAR OLDS FROM A DIVERSE RANGE OF BACKGROUNDS IN SCOTLAND.

We know that young people are the most aware of data privacy issues and are still the most trusting group when it comes to shared health data (British Medical Association, 2015; Healthwatch, 2018). But it's unclear whether that understanding and trust exists across social grades (Wellcome, 2013) and with sharing sensitive data like mental and sexual health data (Aitken et al., 2016).

Combining play and future-based scenarios, we co-designed an online game that dug into these issues. By making a game, rather than a more traditional real world engagement, we set out to create an environment that gave young people permission to say and do things they might not normally feel comfortable doing.

SPECIFICALLY WE WERE
INTERESTED IN ANSWERING
THREE RESEARCH QUESTIONS...

1

What trade-offs are young people willing to make for their desired healthcare system?

2

Why are some types of data more problematic in being trusted to share? For example, data about mental or sexual health.

3

What can be done to alleviate barriers and encourage all young people to trust and support the sharing of health data?

THE GAME



SCOTLAND ON MARS

SCENE SETTING

“THE YEAR IS **2052**. AND AFTER MANY FAILED INTERNATIONAL ATTEMPTS, SCOTLAND IS ABOUT TO DO WHAT NO OTHER COUNTRY COULD – **COLONISE THE PLANET MARS!**”

“SOON **20,000** SCOTTISH **CITIZENS** WILL ARRIVE FROM EARTH TO SET UP LIFE, MAKING SCOTLAND THE FIRST EVER INTERPLANETARY COUNTRY”

“AS THE NEWLY APPOINTED **MINISTER** FOR MARS HEALTH **SERVICE** (MHS) IT’S YOUR JOB TO DESIGN AND LAUNCH A HEALTHCARE SYSTEM FOR THE PLANET’S NEW CITIZENS (NO BIGGIE)”

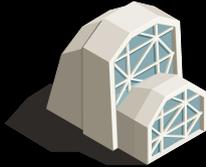
“THE **CHOICES** YOU MAKE WILL HAVE A MAJOR IMPACT ON THE LIVES OF EVERYONE ON MARS FOR **GENERATIONS TO COME**, SO CHOOSE WISELY”

**GOOD LUCK,
MINISTER!**

DEPARTMENTS

DEPARTMENT HEADS IN THE GAME HAVE BEEN BUSY DEVELOPING PROPOSALS FOR NEW HEALTH TECHNOLOGIES THAT CAN BENEFIT MARS' NEW POPULATION

YOUR JOB IS TO VISIT EACH ONE AND MAKE CHOICES ABOUT HOW MUCH CITIZEN DATA SHOULD BE SHARED.



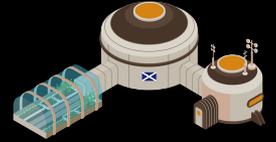
CENTRE FOR HEALTHY FUTURES

This centre is responsible for using state of the art tech to help Mars citizens have healthy futures.



INFECTION CONTROL

This department is responsible for controlling infectious diseases and outbreaks.



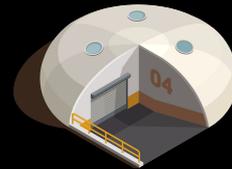
HEALTHCARE DEMAND CENTRE

This department is responsible for providing instant 24/7 care to citizens.



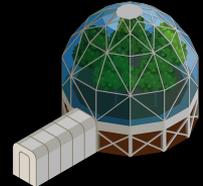
DEPT. OF SECURITY

This centre is responsible for keeping all of Mars' health data safe and secure.



COMMUNITY RESEARCH CENTRE

This centre is responsible for innovative advancements in healthcare and treatment.



CENTRE FOR SELF CARE

This centre is responsible for enabling citizens to monitor wellbeing and practice daily self-care.

GAME MECHANIC



LAUNCHING THE MHS

As Minister for Health you must configure 6 new departments that make up the MHS.



CONSIDERING THE COLLECTIVE GOOD

Although that might sound straightforward - it's anything but! With every decision you make for the collective benefit of the Mars population, you must make a tradeoff around individual privacy.



USING THE LATEST INNOVATIONS

In each department you will be offered the use of new technologies that can help the citizens of Mars have healthy long term futures.



POWERED BY CITIZEN DATA

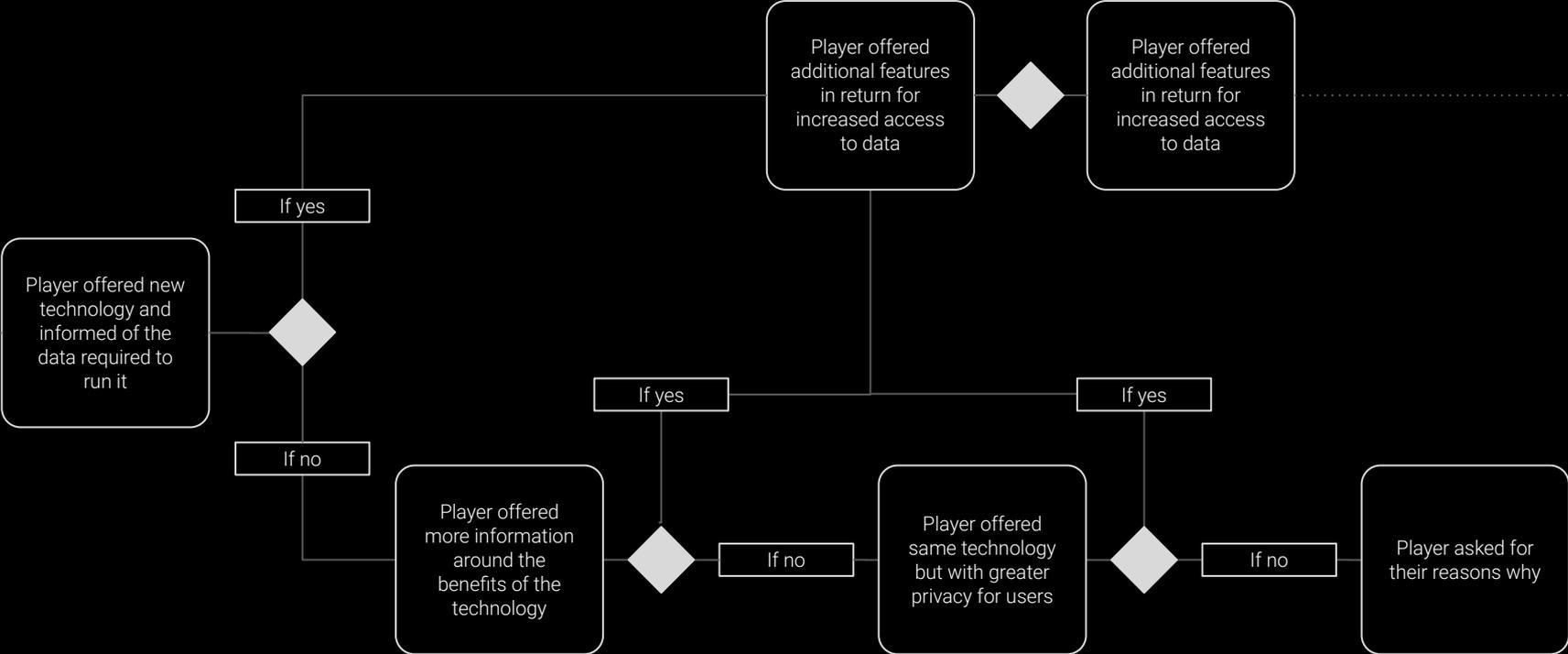
For these technologies to work, certain health data *MUST* be shared. The game will push you to make hard choices - the more access you allow and the more personally identifiable data you allow, the bigger the collective benefit to the population.



BALANCING WHAT FEELS RIGHT

Nothing is black and white though - each decision can be negotiated with more or less privacy meaning you can configure things in a way that feels right to you.

GAME LOOP: TRADING MORE OR LESS PRIVACY



PLAY FOR YOURSELF AT WWW.SCOTLANDONMARS.ORG

Best played on tablet



SECTION 03:

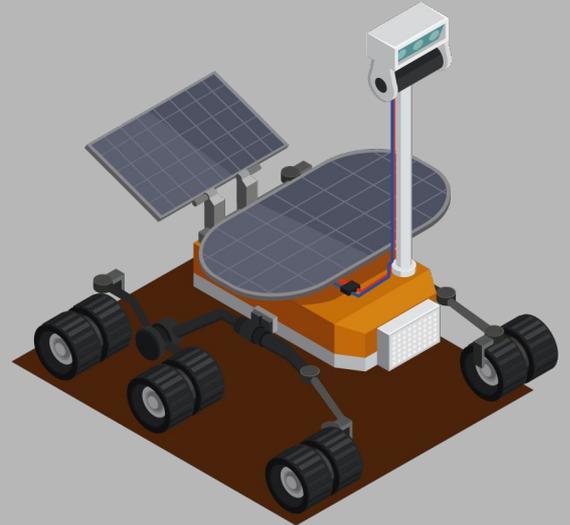
OUR FINDINGS



CHOICES MADE BY 152 GAME PLAYERS

RESEARCH QUESTION #1

What trade-offs are young people willing to make for their desired healthcare system?



#1 WOULD YOU LIKE TO ACTIVATE TWIN TECH® FOR MARS CITIZENS?

Twin Tech® is a powerful new technology that allows users to visualise their health in the future so they can make better choices today. It also helps the MHS plan for the population's future. The MHS could build their own Twin Tech® or work with Avatech, a private corporation, who have existing technology.

TWIN TECH REQUIRES YOU TO TRADE THE FOLLOWING CITIZEN DATA:

- Height and weight
- Exercise and sleep data, tracked by wearables
- Food and alcohol consumption, self-reported by citizens
- Genetic data, via a saliva test
- Online purchasing

*Citizens opt-in through use

Do not activate it

7.84%

Activate it

Healthcare professionals approved by citizens can access non-anonymised data.

13.07%

Activate it

+ MHS staff can access anonymised data.

39.87%

Activate it

+ MHS staff and Avatech can access anonymised data (to offset Mars budgets).

15.03%

Activate it

+ MHS and Avatech can access non-anonymised data (in exchange for free health coaching services).

30.72%

#1 WHAT'S THE DATA TELLING US ABOUT TRADEOFFS?

This scenario is about maintaining a healthy lifestyle. We asked players to make a choice about what and how much citizen data they would be willing to share to enable proactive self-care via digital twin technology. What did we observe?

- A significant majority of players (85.62% combined) chose to share health data with the whole of the MHS (beyond GPs/HCPs) in exchange for Twin Tech® on the basis of citizens opting in via usage. This included data like lifestyle tracking wearables, food and alcohol consumption and online purchasing behaviour.
- The highest percentage of choices (39.87%) opted to keep citizen data anonymised within the MHS, but more players (45.75%) were willing to share with a private corporation in exchange for a benefit.
- Players chose to offer more data to a private corporation in the form of non-anonymised data when it was in exchange for a benefit that was citizen-facing (i.e. a health coaching service)

Do not activate it

7.84%

Activate it

Healthcare professionals approved by citizens can access non-anonymised data.

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+ MHS staff can access anonymised data.

39.87%

Activate it

+ MHS staff and Avatech can access anonymised data (to offset Mars budgets).

15.03%

Activate it

+ MHS and Avatech can access non-anonymised data (in exchange for free health coaching services).

30.72%

#2 WOULD YOU LIKE TO DEPLOY MOVEMENT TRACKING TECHNOLOGY FOR MARS CITIZENS?

Tracking citizens' live location allows the MHS to send live alerts to citizens during virus outbreaks, flu seasons or day-to-day to those with health conditions like asthma. This helps citizens avoid contracting illness and reduces treatment cost to the MHS.

MOVEMENT TRACKING REQUIRES YOU TO TRADE THE FOLLOWING CITIZEN DATA:

- Real-time location data
- Individual health history related to asthma

Do not activate

3.92%

Activate it

MHS staff can access anonymised data.

Citizens opt-in through usage.

7.84%

Activate it

+ MHS staff can access non-anonymised data.

Citizens opt-in through usage.

21.57%

Activate it

MHS staff can access non-anonymised data.

+ Citizens' usage is mandatory but only on a temporary basis during severe outbreaks

37.25%

Activate it

MHS staff can access non-anonymised data.

+ Citizens' usage is mandatory, always.

35.29%

#2 WHAT'S THE DATA TELLING US ABOUT TRADEOFFS?

This scenario is about preventative healthcare and controlling outbreaks. We asked players to make a choice about how much citizen data they would be willing to share to enable proactive public health measures. What did we observe?

- A significant majority of players (96.08%) chose to enable health history data sharing and citizen location tracking with the MHS - with (88.24%) choosing for this data to be non-anonymised - on the basis of citizens opting in via usage.
- When faced with a choice about mandatory data sharing, still 72.54% of players allowed this. A little over half (37.25%) chose this only on a temporary basis during a severe outbreaks to control infection rates and reduce deaths.
- A little under half (35.29%) chose this on a permanent basis to manage more common outbreaks like a winter flu to control infections rates, reduce sick days, increasing income tax and feeding additional budget into the MHS.

Do not activate

3.92%

Activate it

MHS staff can access anonymised data.

Citizens opt-in through usage.

7.84%

Activate it

+ MHS staff can access non-anonymised data.

Citizens opt-in through usage.

21.57%

Activate it

MHS staff can access non-anonymised data.

+ Citizens' usage is mandatory but only on a temporary basis during severe outbreaks

37.25%

Activate it

MHS staff can access non-anonymised data.

+ Citizens' usage is mandatory, always.

35.29%

#3 WOULD YOU LIKE TO DEVELOP POCKET DOC FOR MARS CITIZENS?

Pocket Docs utilise Artificial Intelligence (AI) to provide on-demand healthcare and advice (with a specific focus on sexual health) to citizens in a split second. Citizens receive personalised, informed care without wait times. And the MHS can reserve in-person healthcare for when most needed.

POCKET DOCS REQUIRES YOU TO TRADE THE FOLLOWING CITIZEN DATA:

- Individual health history (conditions, test results, treatment, medication)
- Family health history
- Sexual activity
- Sexual health test results

*Citizens opt-in through use

Do not activate it

13.07%

Activate it

Only citizens can access data.

Does not include sexual health activity and data.

11.76%

Activate it

Only citizens can access data.

+ Includes sexual health activity and data.

10.46%

Activate it

+ Sexual health coaches approved by citizens can access non-anonymised data.

67.32%

No response: 3.27%

#3 WHAT'S THE DATA TELLING US ABOUT TRADEOFFS?

This scenario is about AI-driven, on-demand healthcare (intentionally including sexual healthcare). We asked players to make a choice about what and how much citizen data they would be willing to share to access personalised health services in a split second. What did we observe?

- Out of all scenarios, this is the one that had the highest number of “do not activate” choices (13.07%). These choices were made before players were asked to include sexual health activity and data and was on the basis of citizens opting in via usage like the previous two scenarios. We can deduce that it's related to AI-driven care.
- Of the players who did choose to exchange data for Pocket Doc (89.54%), the significant majority (67.32%) chose to include sexual health activity and data, including data sharing with sexual health coaches on a citizen-approved, case-by-case basis. (**Note that players weren't asked to make choices beyond this level in this scenario*).

Do not activate it

13.07%

Activate it

Only citizens can access data.

Does not include sexual health activity and data.

11.76%

Activate it

Only citizens can access data.

+ Includes sexual health activity and data.

10.46%

Activate it

+ Sexual health coaches approved by citizens can access non-anonymised data.

67.32%

No response: 3.27%

#4 WOULD YOU LIKE TO PROVIDE SELF-MONITORING IMPLANTABLES FOR MARS CITIZENS?

A private pharmaceutical company called PharmaCare have invented a tiny device that can be implanted into a person's body to help them self-monitor and improve their mental health and wellbeing. The MHS could reserve in-person support for when most needed. Mars' schools and colleges could improve student support to young people.

TWIN TECH REQUIRES YOU TO TRADE THE FOLLOWING CITIZEN DATA:

- Serotonin and dopamine levels, tracked by the implantable
- Exercise and sleep data, tracked by wearables
- Food and alcohol consumption, self-reported by citizens
- Daily mood, self-reported by citizen

*Citizens opt-in through use

Do not activate it

9.15%

Activate it

MHS mental health workers approved by citizens can access non-anonymised data.

7.84%

Activate it

+ All MHS mental health workers can access non-anonymised data.

16.34%

Activate it

All MHS mental health workers can access non-anonymised data.

+ Mars' schools and colleges can access anonymous student data.

23.53%

Activate it

All MHS mental health workers can access non-anonymised data.

+ MHS and Mars' schools and colleges can access non-anonymised student data

47.71%

No response: 1.31%

#4 WHAT'S THE DATA TELLING US ABOUT TRADEOFFS?

This scenario is about mental health and wellbeing. We asked players to make a choice about what and how much citizen data they would be willing to share to self-monitor and make adjustments. What did we observe?

- A significant majority of players (90.85% combined) chose to monitor health data via implantables and share with all mental health workers in the MHS (note that this does not include GPs or other healthcare practitioners) in exchange for giving citizens the ability to self monitor. This includes lifestyle data via wearables, serotonin and dopamine levels via an implantable and self-report data like exercise, and food and alcohol consumption.
- When presented with the choice of data also being shared with schools and colleges (in the case of young people), 71.24% chose to share anonymised data. And still almost half (47.71%) chose to shared non-anonymised data in exchange for the benefit of students receiving an offer of mental health support from a mental health professional.

Do not activate it

9.15%

Activate it

MHS mental health workers approved by citizens can access non-anonymised data.

7.84%

Activate it

+ All MHS mental health workers can access non-anonymised data.

16.34%

Activate it

All MHS mental health workers can access non-anonymised data.

+ Mars' schools and colleges can access anonymous student data.

23.53%

Activate it

All MHS mental health workers can access non-anonymised data.

+ MHS and Mars' schools and colleges can access non-anonymised student data

47.71%

No response: 1.31%

#5 WOULD YOU LIKE TO ASK MARS CITIZENS TO DONATE THEIR HEALTH RECORD ON ARRIVAL?

Health Record Donation means personalised treatment could be offered to citizens from arrival and researchers could work fast and effectively to develop treatments to fight new diseases on Mars.

HEALTH RECORD DONATION REQUIRES YOU TO TRADE THE FOLLOWING CITIZEN DATA:

- Height and weight
- Individual health history (conditions, test results, treatment, medication)
- Family health history
- Genetic data
- Exercise and sleep data, tracked by wearables

Do not activate it

Activate it

Healthcare workers approved by citizens can access non-anonymised data.

Sharing health records is optional.

1.31%

1.31%

Activate it

+ MHS staff can access anonymised data (when treating citizens or relatives).

Sharing health records is optional.

3.27%

Activate it

+ Department researchers can access anonymised data.

Sharing health records is optional.

28.10%

Activate it

Department researchers can access anonymised data.

+ Sharing health records is mandatory

26.80%

Activate it

+Department researchers can access non-anonymised data.

Sharing health records is mandatory

37.91%

No response: 0.65%

#5 WHAT'S THE DATA TELLING US ABOUT TRADEOFFS?

This scenario is about data donation. We asked players to make a choice about what and how much citizen data they would be willing to share for all citizen's full health histories, individual and collective, to be linked. What did we observe?

- A small proportion of players (5.89% in total) chose not to openly share citizens' data with department researchers. Though only 1.31% of these were players choosing not to activate at all and the remainder did choose to share health data with MHS healthcare workers for care and treatment of themselves or relatives.
- The significant majority of players (94.11% combined) chose to share population-level data with the MHS and department researchers - most (64.71%) choosing for this to be mandatory to make advancements in healthcare and treatment. This includes health history data, family and genetic health, as well as lifestyle data tracked by wearables.

Do not activate it

1.31%

Activate it

Healthcare workers approved by citizens can access non-anonymised data.

Sharing health records is optional.

1.31%

Activate it

+ MHS staff can access anonymised data (when treating citizens or relatives).

Sharing health records is optional.

3.27%

Activate it

+ Department researchers can access anonymised data.

Sharing health records is optional.

28.10%

Activate it

Department researchers can access anonymised data.

+ Sharing health records is mandatory

26.80%

Activate it

+Department researchers can access non-anonymised data.

Sharing health records is mandatory

37.91%

No response: 0.65%

#6 IF OUR DATA CENTRES GET HACKED, WHAT SHOULD WE DO?

We need to make choices now to plan for this inevitability.

Delete all

Build a hacker detection mechanism that would delete all data and disable health-tech infrastructure.

37.91%

Release some

Accept the release of some citizen data during the hack and build a virtual safe for the citizen data we want kept most secure.

58.17%

Citizen's health record data - **28.21%**

Pocket Doc data - **25.65%**

Movement tracking data - **24.10%**

Twin Tech® data - **16.92%**

Implantables mental health data - **5.13%**

No response: 3.27%

#6 WHAT'S THE DATA TELLING US ABOUT TRADEOFFS?

This scenario is about which data is more critical to protect and which is less critical. We asked players to make a forced choice as to whether, in the case of a data breach, they would delete all data or release some in order to save progress in healthcare advancements.

- With close to a 60/40 split on this choice, there was less of a “significant majority” from players.
- 39.87% choice to delete all data in the event of a breach, losing all citizen health records and new data. Twin Tech®, Pocket Docs and other health tech would crash and have to relearn from scratch.
- Out of the majority of players (62.75%) who chose to release some data in order to protect more sensitive data, the most protected data was mental health data (with only 5.13% of players choosing to release) and the least protected was health records, historic location data and Pocket Doc data, which included sexual activity and health data also.

Delete all

Build a hacker detection mechanism that would delete all data and disable health-tech infrastructure.

37.91%

Release some

Accept the release of some citizen data during the hack and build a virtual safe for the citizen data we want kept most secure.

58.17%

Citizen's health record data - **28.21%**

Pocket Doc data - **25.65%**

Movement tracking data - **24.10%**

Twin Tech® data - **16.92%**

Implantables mental health data - **5.13%**

Height and weight
Individual health history
Family health history
Genetic data
Exercise and sleep data, tracked by wearables
Sexual activity
Sexual health test results
Real-time location data
Individual health history related to asthma
Food and alcohol consumption, self-reported
Genetic data, via a saliva test
Online purchasing
Serotonin and dopamine levels (implantable)
Daily mood, self-reported by citizen

No response: 3.27%

WHAT FACTORED INTO CHOICE MAKING AND TRADEOFFS? QUALITATIVE RESPONSES.

“Despite the many positives of progressing the health service and having more readily available treatments and technologies, I think the choice for the citizens is imperative. It’s the way a democracy should be run” **Cameron, 17**

“Overall the final decision should be down to the individual citizen themselves” **Clara, 17**

OPT-IN OVER OPT-OUT. CITIZENS MAKING THEIR OWN CHOICES

“[Opting-in] gives people a choice. So they get to make up their minds about what they can share.”
Catherine, 16

“The choices I said yes to was because citizens themselves could choose whether to opt-in or opt-out”
Isaac, 16

“I think people need to sign up for that [implantable]. It is personal data and being tracked is someone that shouldn’t be taken lightly.” **Isaac, 16**

“If the citizen had the information and got to choose who they want to share it with, that would be ok.” **Clara, 17**

“I decided it should be made for citizens to access their own data and for MHS workers to access as well”
Gabby, 16

PERSONALLY IDENTIFIABLE DATA ON A CITIZEN-APPROVED BASIS

WHAT FACTORED INTO CHOICE MAKING AND TRADEOFFS? QUALITATIVE RESPONSES.

"There should be two levels [in Pocket Doc] - the crisis level which is severe which sends an automatic notification, and before that a gentle reminder to the person that they should seek help" **Malcolm, 17**

I would make it mandatory to share, but handled by AI until critical level.
Isaac, 16

"I'd be comfortable with people accessing pocket doc data in an emergency, like if you collapsed in the street". **Cameron, 17**

IMMEDIACY OF HARM

"They (computers and AI) don't have any stake over you or your life. They can't gain anything from you. They only care about health" **Isaac, 16**

"I'd rather accept care [for sexual health] from an AI over a human"
Catherine, 16

"If it was made in a way that a human could log into the AI to get the information then that's not ok" **Clara, 17**

TRUST FOR COMPUTERS OVER HUMANS

"If you were really worried about something like an STI or HIV, then the AI could tell them to talk to a doctor"
Jade, 18

QUESTION #2

Why are some types of data more problematic in being trusted to share? For example, data about mental or sexual health.



WHY ARE SOME TYPES OF DATA MORE PROBLEMATIC IN BEING TRUSTED?

“Mental health is about you. The brain is complex and it's far different to breaking an arm or getting a bruise on your knee. Both of them are very personal to you. It's not something you go around sharing”
Malcolm, 17

“Right now, if someone breaks an arm, you know what you can do. But if someone has depression, they have to help themselves. Not like the broken arm, that someone can fix for you. To share that part of you is a big decision, something you'd want to think about”
Clara, 17

IT'S “PERSONAL”

“Some people may be embarrassed about sharing their sexual activity. Or if they have health conditions, they might not want other people to find out and worry about them”
Isaac, 16

“You wouldn't want another person to have access to you sexual health records. It's private. If it was mandatory, it would be a bit disturbing”
Isaac, 16

“Your mental health is personal to you. They should be treated different. Tracking your blood pressure doesn't tell you about anything behind the scenes.”
Clare, 16

“People aren't always trustful of those in power. If they don't want to share private information, that is understandable and we have to accept that”
Clara, 17

“The other reason people don't like this is due to them thinking government are trying to track them and they feel unsafe”
Sophia, 17

MISTRUST OF THOSE IN POWER

WHY ARE SOME TYPES OF DATA MORE PROBLEMATIC IN BEING TRUSTED?

"If I could really know it was confidential, that might give me confidence to let it be shared. So I really know that nobody had the data" **Gabby, 16**

"It can be very personal data that they might not want a stranger knowing" **Catherine, 16**

"What if it gets leaked and somebody sees how many people I've slept with. It can be used against you." **Jade, 18**

FEAR OF DATA GETTING INTO THE WRONG HANDS

"It would have to be secure. Someone with bad intentions could get in and access this information and use it for their advantage" **Clara, 17**

"It feels like it [mental health data] could be used against you and you might not know it at the time." **Clara, 17**

"It's not appropriate for schools and college [to access the data]. I find it risky, your information would be at risk." **Gabby, 16**

"People are so ashamed to talk about it [sexual activity and health]... especially in Britain, we avoid it. In Europe, like in Germany, it's normal to talk about these things with your parents." **Jade, 18**

"It would be ok for citizens to input their information into a pocket doc and advice given by an AI. I don't think they'd judge you, would they?" **Malcolm, 17**

FEAR OF STIGMATISATION

WHY ARE SOME TYPES OF DATA MORE PROBLEMATIC IN BEING TRUSTED?

"If people had eating disorders then their food intake might be a bit more personal. **Clara, 17**

"With depression, it would be about people sharing things about their life. That could be triggering. Like you're exposing yourself a bit. **Clare, 16**

"Sex health stuff would be more embarrassing for other people to know about. If somebody has an STD that hasn't been cured..."
Sophia, 17

RELATING TO AN EXISTING ISSUE

"It would mean they can track mental health and why it's happening but i'm not sure it would actually improve anything." **Clare, 16**

"I don't think the school or college should have any access. It leaves students vulnerable. I wouldn't want my teachers to know, I don't know that they would know how to handle that data either" **Cameron, 17**

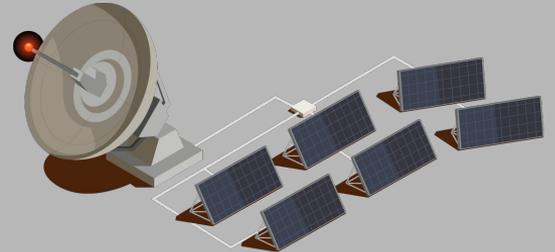
DATA HANDLING / WOULD ANYTHING ACTUALLY CHANGE?

"People would worry that they're just getting tracked but it's not to help them" **Malcolm, 17**

"But with mental health, it's personal and people could start treating you differently." **Sophia, 17**

QUESTION #3

What can be done to alleviate barriers and encourage all young people to trust and support the sharing of health data?



WHAT CAN BE DONE TO ALLEVIATE BARRIERS AND ENCOURAGE TRUST?

"If it's [shared sexual health data] fully anonymous, no connection to you, there's no way they can trace it back to you, then I'd be ok with it"

Catherine, 16

"The data needs to be anonymous to the health sector and people outside of the health sector" **Gabby, 16**

"If it [sharing the data] is mandatory, it can help" **Isaac, 16**

**KEEP POPULATION LEVEL DATA
ANONYMOUS BY DEFAULT**

"There are some things opt-out are ok, but most things should be opt-in. I think if once you give consent, you should still be able to retract it"

Clara, 17

"Having it mandatory seems forceful - a lot of people would question why that should be. It needs to be opt-in"

Clare, 16

EASY OPT-OUT AS AN OPTION

"I don't know if i'm overestimating the pocket doc's abilities but the AI should pick up and advice on issues like that (STDs). But I don't think people would want that picked up by the MHS" **Malcolm, 17**

"Some people want to take control of their own mental health and do things themselves. Making it mandatory is restricting. But it's good to have the option to seek help if you need it" **Clare, 16**

SELF- OR AI-POWERED CARE FIRST

WHAT CAN BE DONE TO ALLEVIATE BARRIERS AND ENCOURAGE TRUST?

"2050 might be different but it (sexual health) is not educated or talked about enough." **Clara, 17**

"I'd be more open about sharing mental health over sexual health data. It's because of the stigma around it." **Catherine, 16**

"It depends on the climate. Is there a stigma? Is there homophobia? Because where there's a human, you have to take potential prejudice into account." **Clara, 17**

EFFORTS TO REDUCE STIGMA

"I said yes to schools. And I think it's because it's about kids at a younger age and it's a preventative treatment. In the long run, it would help ease hospitals and that." **Clare, 16**

"I'd emphasise that it's anonymous and it was to help them. They're data helps to discover information about who does need help." **Catherine, 16**

"I don't think people should be persuaded. It should be left optional. Explain the benefits in an unbiased way." **Malcolm, 17**

MAKE THE BENEFITS CLEAR

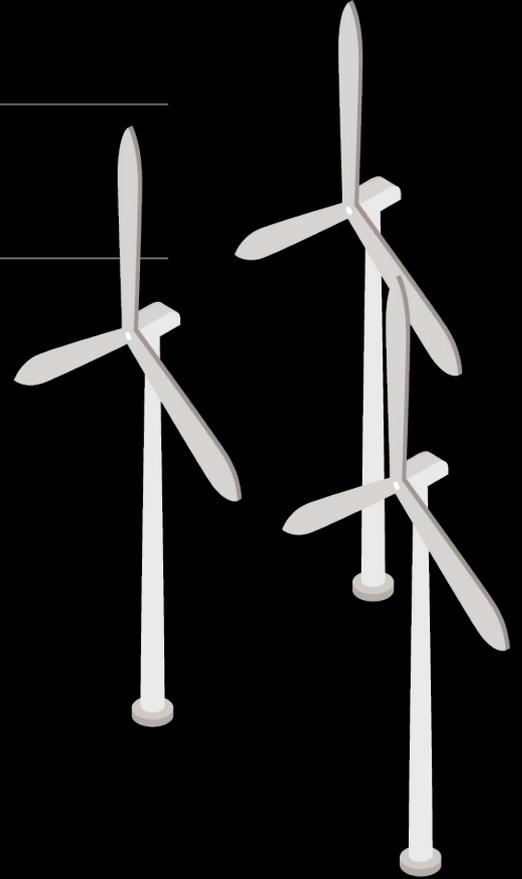
"If there was an outline of a plan and a programme of how schools were going to deal with mental health, maybe. If there was an action plan and I know exactly how the data would be used, then I would consider it." **Cameron, 16**

"They [citizens] have to know it's not about tracking specific individuals. It has to be a collective source to tackle mental health." **Clare, 16**

DEMONSTRATE INTENTIONS AND PLANS

SECTION 04:

THE APPROACH



WHAT WE DID AND WHAT WE LEARNED

APPROACH

THIS PROJECT WAS AN EXPERIMENT IN PARTICIPATORY RESEARCH AND SOCIAL GAMING. A WAY TO EXPLORE POSSIBLE, TRUSTED FUTURES FOR SHARED HEALTH DATA ACROSS SCOTLAND. WE USE THIS APPROACH FOR THREE REASONS.

1

Puts people in the lead. Players collectively take ownership over their own experience without 'expert' facilitation. When people are immersed in the flow of a game, they feel permission to act with less inhibition.

2

Puts aside existing roles and identities. When we play social hierarchies are overridden and safe space is established through the consensually agreed rules and narrative of the game.

3

Challenges existing perspectives. By abstracting everyday scenarios into alternative futures or possibilities through gameplay, players can detach from their own identity and step into the world of others. This builds empathy, helps people understand perspectives different from their own, and has the power to shift mindsets.

WHAT WE DID

190

Young people across Scotland engaged in the project in total. Initially focussing on 16-18 year olds, then increasing the range to 14-20 year olds to build our sample.

1

Rapid literature review to understand the forecasted futures of healthcare and health technologies in 10 years time. Helping to inform game design.

3

Co-design workshops in-person with 24 young people in Scotland (pre-Covid) to surface fears and wants for healthcare. Helping to inform game design and decision logic.

3

Lightweight concepts developed and tested with 14 young people for feedback and direction setting. Working with feedback from young people, we selected and developed the final concept into what became Scotland on Mars.

152

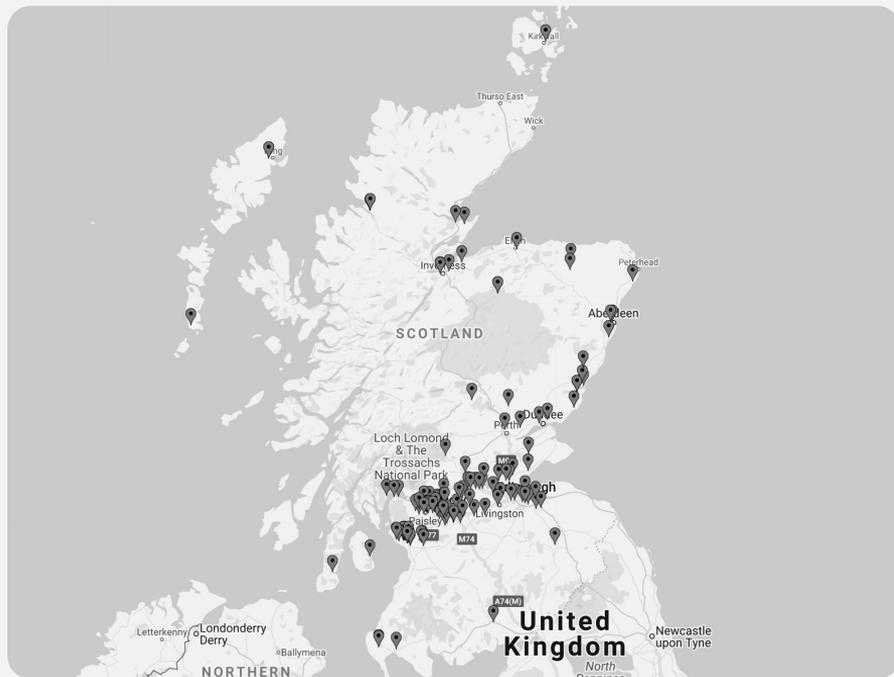
Young people played Scotland on Mars online. This was the main data capture activity that captured choice data within departments.

9

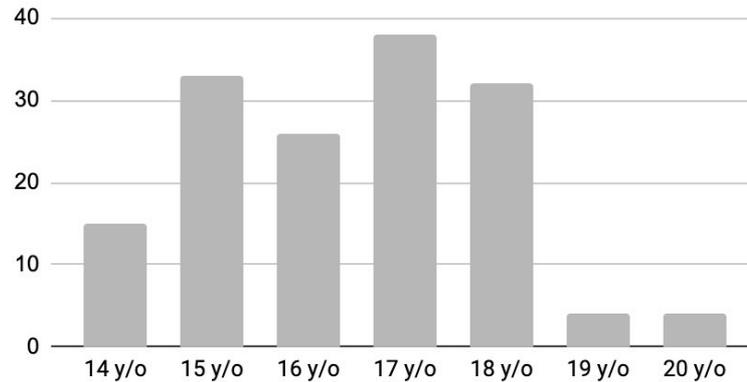
Qualitative interviews players to give insight as to why certain choices were made.

PLAYER SAMPLE

THIS MAP SHOWS THE GEOGRAPHICAL SPREAD OF PLAYERS ACROSS SCOTLAND.



THIS GRAPH SHOWS THE SPREAD OF PLAYERS BY AGE.



A NOTE ABOUT COVID-19 AND THE EFFECT ON RECRUITMENT AND SAMPLE SIZE

RECRUITMENT INTENTIONS

From the outset of the project, our aim for number of game plays was 600+ with a sample that represented both geographical spread and social grade. Our planned engagement route was via schools and youth organisations where our partner, [Dartington Service Design Lab](#), held existing relationships.

THE ONSET OF COVID-19

Recruitment of schools and youth organisations kicked off in March 2020 just before the onset of the global pandemic. The project was paused for the summer, assuming schools would reopen and we could continue with engagement from September 2020. Schools did not reopen as normal and instead were dealing with lockdowns, closures and adapting to remote learning.

A NOTE ABOUT COVID-19 AND THE EFFECT ON RECRUITMENT AND SAMPLE SIZE

DECISION TO GO REMOTE

In Jan 2021, we made the decision to adapt the game so that young people were able to play it in full remotely. And as part of this decision, we would supplement remote play with qualitative interviews with 9 young people about choices made in the game. We had feedback from council-level that making the game playable from home would make it easier for schools to encourage play.

RECRUITING THE FINAL SAMPLE

We continued to hold close conversations with schools and youth orgs through Jan-May 2021, but unfortunately we did not reach our intended sample size of 600+. Nearly all 152 players who engaged with the game via local youth organisations and [Young Scot](#). It proved particularly hard to get schools to commit (given Covid and the project timeframe). Youth organisations, generally, were more willing to engage, especially for interview-style interactions.

LEARNING ABOUT THE APPROACH

WE SEE AN OPPORTUNITY FOR CONTINUED PLAY TO INCREASE SAMPLE SIZE AND IDENTIFY TRENDS ACROSS GEOGRAPHIES AND SOCIAL GRADE

GENERALISING THE FINDINGS

We must caveat that with our final sample size of 152, generalised statements or findings can't be made about the views of Scotland's 16-18 years olds as a whole or specifically broken down by social grade. This is unfortunate as even though the grounding evidence behind this project showed that young people are the most aware of data privacy issues and are still the most trusting group when it comes to shared health data (British Medical Association, 2015; Healthwatch, 2018), it remains unclear whether that understanding and trust exists across social grades (Wellcome, 2013).

AN OPPORTUNITY FOR CONTINUED PLAY

Given that the Scotland on Mars game is built and playable remotely, we see an opportunity for continued play and data collection with 16-18 year olds across geographies and social grades in Scotland. This data would allow us to identify correlations between choices made in-game and indices of multiple deprivation.

LEARNING ABOUT THE APPROACH: PLAYERS QUOTES

"I've never done anything like that before. It's good to make you think and question why you think in that way" **Clare, 16**

"It was pretty good but a bit stressful at times. When you've got two options and they've both got downsides but you're in charge so you have to decide. It made me think" **Clara, 17**

"It was really hard to make those choices. Like, not just having to choose based on what I think, but based on the population. Yeah, that was hard. I'm still thinking about it now" **Malcolm, 17**

"When you've got two options and they've both got downsides but you're in charge so you have to decide. It made me think"
Gabby, 16

"I've never done anything like that before. The last question really got to me. It really makes you think" **Sophia, 17**

"This made me challenge my own thinking. I was really into it. I really felt like I was the minister of the MHS making these tough calls" **Catherine, 16**

SECTION 05:

PROJECT TEAM



THE PROJECT TEAM

LOUISE COOPER, PROJECT LEAD.

With 10 years experience building human-centered products and services in both the for-profit and not for profit sector, Louise is a designer-type. She's obsessed with the complexities of people and passionate about participatory research methods and the power that play has to put people and communities in the lead.

AMELIA WOODS, RESEARCHER

Amelia is a social researcher and strategist with a particular interest in young people and play. She has worked for 10 years on human-centered projects, usually in health, with a spectrum of organisations from the public sector to the third sector and small, agile startups. She was previously Head of Insight at BfB Labs.

KARL TOOMEY, CREATIVE DESIGNER.

Karl has worked in the creative industries for 10+ years, working across content, campaigns and experiences.

JAKE ADAMS, GAME DEVELOPER.

Jake is a frontend developer with several years experience building product across travel, retail and editorial content.

KATE TOBIN, ENGAGEMENT.

Kate leads Dartington Service Design Lab in Scotland and specialises in Service Design.

NATASHA HESSAMI, ENGAGEMENT.

Natasha is a researcher and recent graduate of MSc in Social Policy Research Methods.

MADEBYPLAY is an innovative venture within Shift that fuses creativity, play and research rigour to ignite people-led social change. Shift has been pioneering participatory research and design methods for over 10 years.

DARTINGTON SERVICE DESIGN

LAB. For this project, we were supported by our partner, Dartington Service Design Lab, who are Scotland-based and led on recruiting young people as co-design partners and players for the game.

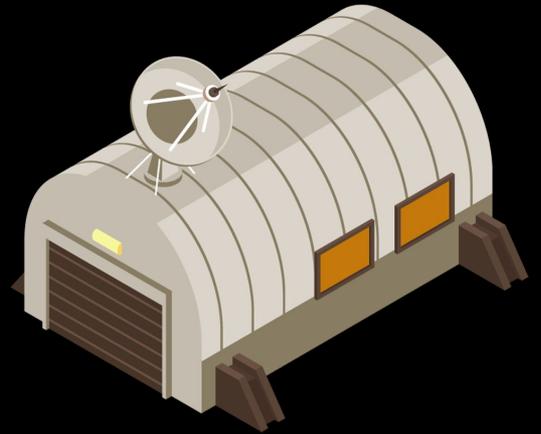
MadeByPlay

Shift



SECTION 06:

APPENDIX



APPENDIX: LIT REVIEW INTO THE EXPERIENCE OF YOUNG PEOPLE ACCESSING HEALTHCARE IN 2020

2020

Daily Life

First and foremost, I'm an individual and I want to be heard as such

Concerns and anxieties

Transition to adulthood
I resent the fact that I have to rely on my parents so much because the government has reduced support for young people like me

I really want to be independent but I have to rely on my family to get by

Career
I think AI and machine learning and IOT will affect my education and my career by I'm not sure how

I don't feel confident that there are opportunities for me to engage in rewarding work

It's difficult to believe in myself when I don't really believe in the future of society

I know that I'll have to regularly review and update my skills to adapt to a jobs market that's always changing

Politics
I see myself as a global citizen. I'm really worried about climate change and the destruction of nature. I know this will affect my life but I don't feel connected to local issues or local politics

I don't really care about politics either way. I don't engage with it because it doesn't connect with me or seem relevant

I don't feel any sense of belonging to society, in fact, I feel pretty disconnected

The government has neglected us. I feel like our fate has been decided in advance without us having a say. I just don't trust the government

I'm not optimistic about the future of our society. There's too much disconnection and fragmentation. I'm worried about war and religious conflict

Wants, needs and hopes

Transition to adulthood
I want to make informed choices about my body, sexuality and reproduction without discrimination

First and foremost, I'm an individual, I don't want to be defined by my group, I'm distinctive and I want to be heard as such

I care about the world we live in and I try to do what I can to practice mindful consumption

Females run the world, there are now females in more positions of power, more conversations out in the open and a greater understanding of the female experience

I don't notice diversity in places, I notice when it's not there

I embrace technology and the internet and social networks empower me to do something positive

Career

I want a good balance between my work and social life but I also want the opportunities to advance in my career and find work that's meaningful, with purpose

I want to work, yes, but for myself too

I feel like there's a need for more common goals for us to get behind, together. This would help me believe in the future

I think advances in technology will create new jobs, and that's a good thing

Politics

I'm looking for integrity, honesty and transparency and I only consume content that's useful, interesting or fun for me. It has to be relevant

Accessing Healthcare

Concerns and anxieties

General health and healthcare records
A lack of clarity about privacy makes me nervous about using health services

I think everyone should be able to access their health records but also control who else accesses them. If it's to improve health services and research, that's good but there might be things I don't want my parents to see

Mental Health
I'm not sure whether my problem is serious enough to see a doctor and I wouldn't know where to go anyway, I've heard it's hard to access

I can't talk to my friends about it cause we just don't talk about these things, they'll think I'm weird or pathetic

If I do see a doctor about my mental health I worry that my friends or other people in my circle will find out

I don't want my parents to know that I'm seeking help, they won't understand and I don't want to worry them or become a burden

I think mental health services are unwellcoming and inflexible and I don't like that they emphasise medication

I'm worried that going to health appointments will have a knock-on effect on my progress in school

Sexual Health

I don't know my rights around privacy, if I go see someone about my sexual health do my parents need to be there, or will they find out?

I want good sexual health but I can't talk to my family about it, I get info from my friends or the internet

I don't want to go to my local doctor, it's too close to home

I use social media to find stuff out but it can be confusing

I want to be treated like an adult and it can be embarrassing if the healthcare professional isn't confident dealing with young people

I think a bit of humour helps to talk about sexual health

I want to be treated as an individual by people who are confident dealing with young people

I want the NHS to support and understand me and help me to transition to adulthood

...

Wants, needs and hopes

General health and healthcare records
I want the NHS to support and understand me and help me to transition to adulthood

I don't really see why all healthcare should be free

I want to be treated as an individual by people who are confident dealing with young people

Mental Health
I think services could be provided in places where me and my friends go, the places we hang out

Sexual Health
I want to know more about sexual health but I'm not interested in the biology side of things. I want to be better informed about STI's and learn about how to make sex more satisfying, maybe even learn more about relationships

I want to be treated as someone who has control over my own sex life

I think my friends and people a little bit older than me are the best source of info about sexual health

Concerns and anxieties

It's just so much hassle, I wonder if it's worth it. Whenever I move to a new department it just makes me more anxious

I can sense embarrassment in adults and it just makes it worse

Sometimes I need my parents with me to understand what I'm being told but I hate it when they exclude me

Healthcare providers don't know how to talk to me as a young person

I feel like with every new appointment, I'm just getting asked the same questions, it's really annoying

Receiving Healthcare

I'm not interested in a one-size fits all approach

Wants, needs and hopes

I just want to know what's happening and I'd rather stick with one doctor rather than being passed around

I want to be kept up to date on what's happening

I want to know who's accessing my record and what for

I want mental health services to help me to be more self resilient

I'd rather there were more community based mental health services. I don't want to have to go to a doctor

I want health professionals to listen to my views and improve services based on them, instead of just listening to my parents

I want health professionals to communicate with me as an individual, not just a young person

I'm not interested in a one-size fits all approach, if health professionals really listen to me then I'll feel more confident I'll get what I need

I want to choose who I'll see, sometimes I want to talk to a woman or someone my own age

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PDF DOWNLOAD LINK

APPENDIX: LIT REVIEW INTO THE POSSIBLE FUTURE OF HEALTHCARE BY 2030

Time efficient cities have freed up time for people to now spend more time with family and friends. Less vehicle dependency means they're more active and less stressed, which has reduced rates of depression.

Urban sensing monitors how human bodies respond to the built environment and even alerts citizens of unhealthy movement and interaction.

Surveillance systems now include genomic data and some campaign groups are calling for an end to citizens being "hunted" by authorities, based on controversial data sets such as ethnicity.

Congestion has been eliminated and traffic flows are optimised to people spend less time in cars. Smart cycles and on-demand public transport are the main modes of mobility.

Environment sensors and control systems manage indoor light, temperature, acoustics and air quality that respond to users' biometric Hippo data. Home and work spaces are optimised for better health and for wealthier citizens, personalised.

Citizens can view the pollution levels and air quality of spaces and places in real time.

Local authorities are responsible for the monitoring and reporting of the city's health. People's health outcomes are considered at every level of policy, urban planning and policy making.

Smart city planning, infrastructure, and design are dominated by commercial interests and many state-owned services have been contracted out to large technology firms

Advances in social media technologies have transformed the way people interact with health services.

Patients can maintain check-up appointments and care schedules through their AI powered Hippo calendar.

Patients can search for and interact with practitioners via social media as well as review and rate the quality of interactions and the care they receive.

Patients can find and access health services and healthcare information through peer verified social media circles.

Patients can explore their own health futures inside digital health games. For example, they can assess the effect that diet, exercise regimes or environments will have on their own health avatar.

Patients can access most of their healthcare via remote. AI powered bedside consultation, VR therapies and data-driven self management.

Patient
In the latter half of the last decade, there was a seismic shift in healthcare from doctor-centred to patient centred. People can now access high-quality, personalised care, no matter where they live.

Telemedicine, provided through the Hippo platform has standardised healthcare for everyone and access is opening up across countries and continents - helping to build a real time view of the health of citizens.

Environment

68% of the world's population now lives in dense urban settings. Cities are data and IoT enabled which has rapidly accelerated urban development to adapt to human needs in an effort to create healthier places to exist.

2030

Planet

Attitudes to health are shifting from a public health mindset to a planetary health mindset. A belief that the future depends on extraordinary cooperation between us is gaining traction across social and political divides.

Internally, we are not fully human - we are home to massive numbers of microorganisms, some of which are vital to our health, and externally our survival, from the air we breathe to the food we consume, depends on other species.

A planetary health perspective means assessing the ways all health issues everywhere are shaped by a human-impacted environment.

People view themselves as not just agents of climate change, but also vulnerable objects of climate change.

Public health is critical to a planetary health vision because of its values of social justice and fairness for all, and its focus on collective action.

Healthcare providers now act as facilitators, not experts. Their job is to help patients make sense of complex data sets and support them to make healthier decisions.

Provider

3 years ago a new value-based system was introduced across Europe, in which healthcare providers are now paid based on the data-validated health outcomes of their patients.

Trying to protect all data has become an impossible task, although state run AI systems constantly monitor and encrypt health data which is deemed critical to keep private.

Hippo helps health managers at every level with operational and strategic information about drug availability, finances, and human resource management.

Recent advancements in wearables and implants has reduced the cost of treatment for chronic conditions by 60% by enabling patients to manage and administer their own medicine.

Constant self-surveillance by has dramatically increased the number of interactions between citizens and healthcare providers, by driving more people to seek treatment.

Providers rely on 24/7 AI support regarding the diagnosis and treatment of patients; the Hippo supports providers to diagnose and treat patients and can search verifiable records about births, deaths, and health encounters.

E-medication, implantables and wearable technologies have extended care beyond traditional boundaries and enabled providers to constantly monitor and evaluate the nation's health.

Providers are rewarded for helping patients improve their health, reduce the effects and incidence of chronic disease, and live healthier lives in an evidence-based way.

MadebyPlay

PDF DOWNLOAD LINK

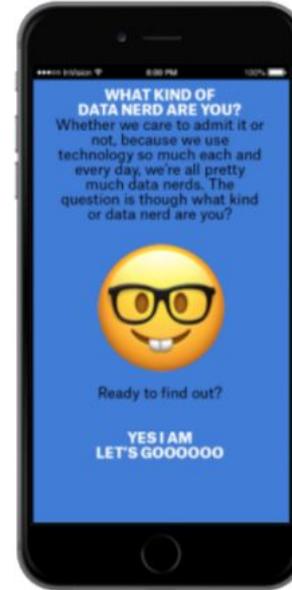
APPENDIX: Mid-project checkpoint with summary of concept development and testing



1. Medi Mars



2. Island Life



3. Data Nerds

APPENDIX: Mid-project checkpoint with summary of concept development and testing

Game scenarios					
Future feature	Scenario (All scenarios to include: Data type • Data access • Data level • Benefit)				Notes/questions
Avatars A precise, virtual simulation of 'you' that functions as an early warning system, signalling potential vulnerabilities when you still have a chance to make a change, and showing you the best version of yourself given the choices you currently face - made possible by the data we constantly generate as we go about our real lives. This scenario is about maintaining a healthy lifestyle.	Entry scenario (1.0) - Public Health is top priority and, with this, there's a goal to best support citizens to maintain a healthy lifestyle (to stop certain health conditions arising in the first place). Technology to build virtual avatars (behaves as a 'digital twin' to humans) is now available. - The benefit is that citizens can use their digital twin to self-monitor their behaviour and online and the in-built predictive algorithms will identify patterns and trends in these data to accurately model future outcomes, meaning they can make informed changes to their lifestyle in the present (e.g. looking at/buying certain foods in your online grocery order). With this pooled data set from all citizens, public health/NHS could predict lifestyle patterns up to 30 years in the future and prepare accordingly (e.g. showing them at age 45 with sight loss). - Data required: Height and weight; Lifestyle data tracked by wearables (exercise, sleep); Food and alcohol consumption, self-report; Genomic data; Online browsing and purchasing behaviours. Anonymised, opt-in through usage.	If yes: Up the ante (1.1) - Developers at your Public Health dept can build this - it will take 3-5 years and take 30% of the annual healthcare budget. But a prominent tech giant already have the avatar technology available and has offered free and immediate use of their avatars if government endorse the use of the avatars. Both Public Health and the tech company would have access to the data, meaning the data they have access to could be used to make money. - Data required: Same data types and access levels. Same anonymised, opt-in through usage.	If yes: Up the ante (1.1.1) - If citizens name details can be attached to the datasets, the tech company has offered to free online health coaching to citizens at risk of developing long-term health conditions because of their current lifestyle. This could reduce onset of chronic health conditions, leading to better health for citizens and less spend for Public Health. But it would mean that the tech company could use data to target their marketing to specific individuals to drive sales. - Data required: Same data types, fully open, still opt-in through usage.	If yes Go to next scenario	
		If no Go to open text box asking "why"	If no Go to open text box asking "why"	If no Go to open text box asking "why"	
Surveillance (using smart city infrastructure) Governments can make decisions about how people move, or, if suddenly many people are sick the system triggers the production of extra medication in the local area it is needed - a smart system that responds in real-time to the health needs of the population. This scenario is about maintaining public health and controlling outbreaks.	Entry scenario (2.0) - Assessments of the feasibility of human life on Mars has highlighted a specific type of Mars dust that aggravates the human respiratory system. Asthma sufferers in the new arrivals of citizens will be at risk of increased asthma attacks, anxiety associated with going outside, and weakened respiratory health later in life which increases the level of healthcare you'll need to provide and pay for. Your government has the ability to use citizens' location/movement tracking, and communicate in real time to asthma sufferers about the routes with the least Mars dust in the air when they're out walking. - The benefits for asthma sufferers are avoiding risky hotspots and enabling better quality of life.	If yes: Down the ante (1.2) - With this avatar technology, individuals would be able to see into a likely future, the long-term effect of their lifestyle patterns, as well as testing out potential new behaviours. E.g. if they're currently at risk of diabetes but they changed one aspect of their eating and took a 30 minute walk a day, the risk would be removed. - Data required: Same	If yes: Up the ante (1.2.1) - What if the data and prediction were only available to the human using the avatar, not with Public Health, and they had control to share it with selected healthcare worker or health coaches when they choose. - Data required: Same data types, but individual owner approves before sharing with mental health worker.		
		If no Go to open text box asking "why"	If no Go to open text box asking "why"	If no Go to open text box asking "why"	
Surveillance (using smart city infrastructure) Governments can make decisions about how people move, or, if suddenly many people are sick the system triggers the production of extra medication in the local area it is needed - a smart system that responds in real-time to the health needs of the population. This scenario is about maintaining public health and controlling outbreaks.	Entry scenario (2.0) - Assessments of the feasibility of human life on Mars has highlighted a specific type of Mars dust that aggravates the human respiratory system. Asthma sufferers in the new arrivals of citizens will be at risk of increased asthma attacks, anxiety associated with going outside, and weakened respiratory health later in life which increases the level of healthcare you'll need to provide and pay for. Your government has the ability to use citizens' location/movement tracking, and communicate in real time to asthma sufferers about the routes with the least Mars dust in the air when they're out walking. - The benefits for asthma sufferers are avoiding risky hotspots and enabling better quality of life.	If yes: Up the ante (2.1) - What if there was an infectious outbreak and the government needed to rapidly identify citizens who had been in contact with the virus so they could be isolated to prevent spread? Should location tracking be made mandatory until the virus is under control. To prevent infection and death? - Data required: Same data type and access level, accessible by government, mandatory, time-limited	If yes: Up the ante (2.1.1) - What about after the virus subsides? This method has been effective in dramatically reducing the spread of virus. If we were to continue with mandatory tracking for all citizens and add daily temperature taking, citizens could be notified of common flus (and the likes) and avoid areas where contagion is likely which would reduce illness and sick days saving the economy \$\$\$. - Data required: Same by not time-limited	If yes Go to next scenario	
		If no Go to open text box asking "why"	If no Go to open text box asking "why"	If no Go to open text box asking "why"	If no Go to open text box asking "why"

THANK YOU

