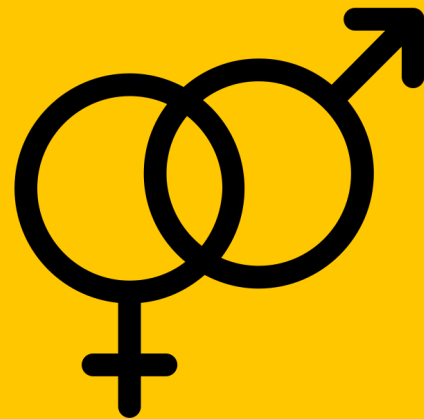


joy

Designing gender inclusive healthcare services

SDinGov Virtual



Hello from Emma (she/her)

- 15+ years as a designer, both graphic and service
- 4 years living in New Zealand
- 10 years working in user centred design as a service designer
- 18 months working at NHS Digital during the pandemic
- Started my own company, Joy, in 2021



Hello from Lee (he/him)

- Gender Studies MA graduate from University of East Anglia
- LGBTQIA+ and gender diversity trainer and educator
- Equality, Diversity and Inclusion Project Manager in the NHS



Trigger warning

We will be talking today about serious harm and discrimination.

Why we're here.

The so called 'culture wars' are raging on with terrifying consequences for trans people especially.

In the year ending March 2023, 4,732 hate crimes against trans people were recorded. That's a rise of 11% from the previous year.

We're here to table a factual argument for equitable access to services but people are also in danger on a daily basis.



Today

- Why do this work
- Personal stories
- Case studies:
 - Covid-19 vaccination booking
 - DrinkAware digital drink tools
- Best practice and practical recommendations

Why do this work?

Sex and gender are
not the same thing

The UK government defines **sex** as:

- referring to the biological aspects of an individual as determined by their anatomy, which is produced by their chromosomes, hormones and their interactions
- generally male or female
- something that is assigned at birth

The UK government defines **gender** as:
a social construction relating to behaviours and attributes based on labels of masculinity and femininity; gender identity is a personal, internal perception of oneself and so the gender category someone identifies with may not match the sex they were assigned at birth

Everyone is not treated equally

- 27% of all respondents reported that they have experienced homelessness at some point in their lives, rising to 35% for both BPOC and disabled respondents.
- 63% of respondents reported experiencing transphobia while seeking employment, rising to 73% of BPOC respondents.

[Trans lives survey 2021](#)

Photo by [Sinetta Leunen](#) on [Unsplash](#)



Healthcare is hard

- 14% reported that they were refused GP care on account of being trans on at least one occasion
- 45% said their GP did not have a good understanding of their needs as a trans person, rising to 55% for non-binary respondents
- 57% of trans people reported avoiding going to the doctor when unwell

Photo by [CDC](#) on [Unsplash](#)



Humans behind numbers

- Around 262,000 people (0.5%) said their gender identity and sex registered at birth were different.
- Clinical research (2019) estimates that the 'birth prevalence of atypical genitalia' may be 1 in 300 births, equivalent to over 200,000 people in the UK.

Photo by [Kyle William Murban](#) on [Unsplash](#)



Personal stories

Health screening invitations

Trans men and non-binary people assigned female at birth who are registered with a GP as female:

- are invited for breast screening
- are invited for bowel cancer screening
- are invited for cervical screening
- are not invited for AAA screening

Trans men and non-binary people assigned female at birth who are registered with a GP as male:

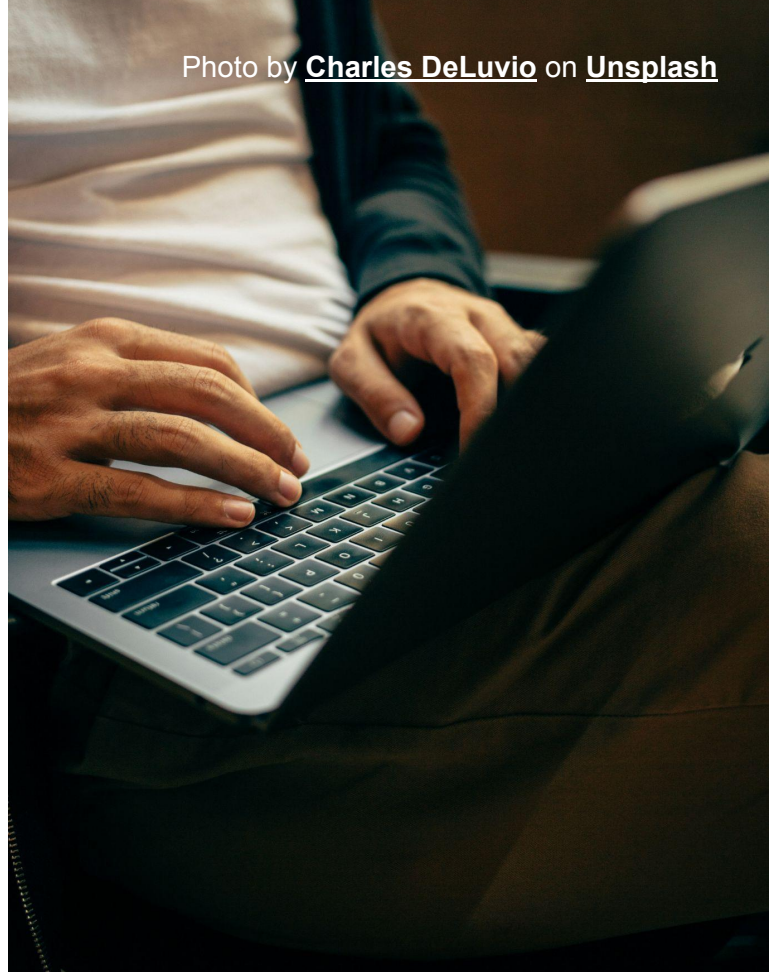
- are not routinely invited for breast screening but can request screening
- are invited for bowel cancer screening
- are not routinely invited for cervical screening but can request screening
- are invited for AAA screening but do not have a high risk of AAA

[NHS population screening: information for trans and non-binary people](#)

Booking appointments

- A pregnant trans man was unable to book his first midwife appointment
- The system would not allow anyone with a 'male' gender marker to make an appointment
- Time consuming steps needed to be taken to solve this issue and risks aren't mitigated quickly

Photo by [Charles DeLuvio](#) on [Unsplash](#)



Avoidable mistakes

- Simple and strange mistakes can lead to misuse of valuable time and resources
- This can be avoided by ensuring everyone is aware of how their processes work
- These processes should be evaluated and updated regularly



Tests based on 'norms'

- A trans man went to emergency care and tests were run on his kidney function.
- Lab results are assessed differently based on the norms of cisgender men and women.
- Patients can be put at risk when not taking into account factors like sex assigned at birth, hormones etc.



Case studies

Low

High

Covid 19 vaccination
booking

Drink Aware



Level of clinical
complexity

Covid-19 vaccination booking

[Home](#) > [Health A to Z](#) > [Coronavirus \(COVID-19\)](#) > [Coronavirus vaccination](#)

Book or manage your coronavirus vaccination

Use this service to book a coronavirus (COVID-19) vaccination or manage your appointments.

Who can use this service

You can only use this service if you have received a letter inviting you to book your vaccination appointments.

You also need to be registered with a GP surgery in England to use this service. You can [register with a GP](#) if you do not have one.

Find out more about [who is eligible to have a coronavirus vaccination](#).

Wait to be contacted

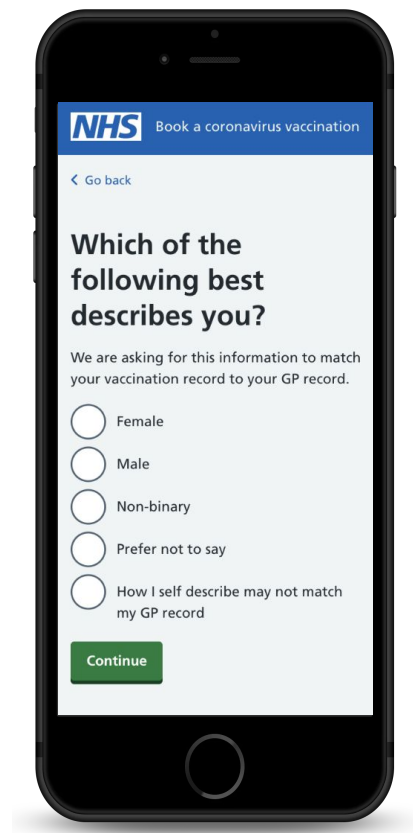
The NHS will let you know when it's your turn to have the vaccine. It's important not to contact the NHS for a vaccination before then.

The service needed to identify a person
by matching them to their GP record
using a service called the Personal
Demographic Service (PDS)

The problem

- The current methods of matching patient provided demographic details (when NHS number is not known) includes 'gender' as a mandatory field
- The data is labelled gender and the attributes held are male, female, unspecified and unknown
- The data is not stored and is not used for clinical or monitoring reasons

We worked across disciplines to create the most inclusive solution we could within the technical constraints we were given



[< Go back](#)

Which of the following best describes you?

We are asking for this information to match your vaccination record to your GP record.

- ☐ Female
- ☐ Male
- ☐ Non-binary
- ☐ Prefer not to say
- ☐ How I self-describe does not match my GP record

[Continue](#)

Making the case for change we changed the FHIR API and removed the question from the service



Emma Parnell 10:11 AM

For anyone building services that require a PDS lookup or anyone following the work last year on sex/gender questions. See below for an update from the PDS team:

It is now possible to perform "standard" (non-fuzzy) searches without having to specify the patient's gender. Searching without gender is likely to slightly improve match rates, and also means you can avoid having to ask citizens their gender, which can be a sensitive topic for some people.

The change is available now in our sandbox and integration test environments. It will be available in production from this Friday.

This is a non-breaking change – if you are searching with gender, this will continue to work as-is.

For more details, see <https://digital.nhs.uk/developer/api-catalogue/personal-demographics-service-fhir#api-Default-searchPatient>.

This is a very big win for inclusive design so thank you to everyone who helped champion this cause. And special thanks to the PDS team for all the hard work to make this happen.

cc @jeanelgie @RichF @Laura Hajba @Lucy Winder @Owen Beddis @sarawilcox @richardm @rob @jspirit @jameshiggott @matt.higgins @Andrew Duckworth @caroline_finucane @mattlund @tomhallam @nigelatwell @Adam Fenwick (edited)

👍 45 🙌 12 🍷 6 ⭐ 9 🏆 1 🎉 5 🥳 1 🎊



+8 24 replies Last reply today at 4:01 PM

Drink Aware digital drink tools

In partnership with 2CV

The brief

Drink Aware have digital tools on their website you can use to assess your drinking behaviour.

They were looking to make these tools work for gender diverse audiences.

The screenshot shows the 'Self-assessment test' page on the Drinkaware website. The page has a purple sidebar with a 'Menu' button and links for 'Search', 'My DA', and 'Drinkchat'. The main content area is light blue and features a progress bar at the top. The test instructions state: 'Complete the quick and simple test below to understand more about the impact of your drinking on your health and well being. At the end of the test your result will show you if your drinking puts you at low risk of harm or if you need to take action to reduce the amount you drink.' The form includes three sections: 'Age' with a text input field, 'Sex' with radio buttons for 'Male' and 'Female', and 'Postcode' with a text input field and a location pin icon. Below the form, a section titled 'Why do you need to know my age and sex?' explains that the information is used to provide personalized help and advice. A 'Next Question' button is located at the bottom of the form.

drinkaware Facts Advice and support Tools Research Work with us Shop

Self-assessment test

Complete the quick and simple test below to understand more about the impact of your drinking on your health and well being. At the end of the test your result will show you if your drinking puts you at low risk of harm or if you need to take action to reduce the amount you drink.

Age

Sex

☐ Male ☐ Female

Postcode

Why do you need to know my age and sex?

By finding out your age and sex we can give you more personalised help and advice.

Next Question

Sex



Male



Female

Postcode



Why do you need to know my age and sex?

By finding out your age and sex we can give you more personalised help and advice.

Why ask?

- The first thing I always consider with these projects is why do they need the information?
- This situation was interesting as it had a health implication because alcohol affects male and female bodies differently
- Things got complicated when we considered trans people taking hormones

But what is actually needed

- It's nuanced but the best we got to was differences in body fat to water ratio
- Clinical advice is important
- Lack of research on trans bodies - Drink Aware want to change that

We ask for this information as people process alcohol differently based on differences in biology.

We ask for this information as people process alcohol differently based on their sex assigned at birth.

We ask for this information as alcohol affects male and female bodies differently due to, primarily, differences in body fat to water ratio.

Language matters

- Registered was triggering to some people
- Assigned talks to it being out of someone's control
- Sex at birth worked from CIS users
- Gender identity

Sex registered at birth*

We ask for this information as people process alcohol differently based on differences in biology.

Sex assigned at birth*

We ask for this information as people process alcohol differently based on their sex assigned at birth.

Sex at birth*

We ask for this information as alcohol affects male and female bodies differently due to, primarily, differences in body fat to water ratio.

Final designs

- Ask about sex and gender separately
- Explain why you're asking
- Provide links for people who want to know more
- Provide inclusive, pre-populated options
Including prefer not to say

What is your sex at birth?*

We ask for this information as people process alcohol differently based, primarily, on body fat to water ratio.

Male

Female

Intersex

Prefer not to say

What is your gender identity?

We ask for this information as some people's gender identity does not match their sex at birth.

Male

Female

Non-binary

Prefer not to say

Identify in another way

Practical recommendations

1. Radiography
2. Patient records

Small but mighty changes

- In the UK [the Ionising Radiation \(Medical Exposure\) Regulations](#) are used to protect individuals from the harmful effects of ionising radiation
- Written procedures now say ‘individuals of childbearing potential’
- The Care Quality Commission highlighted a case where a pregnant trans man had been irradiated during a CT scan because he was not asked about possibility of pregnancy
- The CQC made an action for employers to ‘make sure that procedures in imaging and radiotherapy departments are inclusive of transgender and non-binary patients, including the procedure for making pregnancy enquiries’

Inclusive engagement

- The hospital recognised that they didn't have a process in place to effectively manage the healthcare of transgender patients
- They have established a model where the patient is able to make an informed choice about their medical record and how their gender is recorded on the hospital's clinical records
- The project involves transgender and non-binary patients at every step

Shared with the consent of Sally Berrill,
Head of Data Security and Protection,
Northampton General Hospital NHS Trust

LinkedIn Lee Brown | **LinkedIn** Emma Parnell | **Substack** Design for Joy | designforjoy.co.uk

Photo by [Maxime](#) on [Unsplash](#)



Our recommendations

1. Think about if you need the data, if you don't, don't ask
2. If you do need it, make time to understand why
3. Make sure your service isn't making assumptions about people
4. Look out for barriers you're putting in people's way
5. Fight to change legacy systems and data structures

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Thank you.

