Members' Census

2020

Contents

What the Census told us

1. **We received 103 responses to the Census**

   This was a response rate of 67%.

2. **We are a true mix of patients, relatives and carers**

   91% classified themselves as patients, 43% classified themselves as carers, and 24% as relatives[1].

3. **Our Members represent a range of health conditions but are weighted towards cancer. We need to increase representation of the patient voice in other health conditions.**

   70% of Members are/were cancer patients, 25% have arthritis, over 10% report a mental health condition with just over 10% a cardiovascular condition[2]. Compared with the most common health conditions in the UK, our Membership has an over-representation of cancer patients.

4. **For Members who are relatives or carers, there was a very different spread of health conditions for the person being cared for[3]**

   Cancer was similar at over 70%, but cardiovascular conditions were at 20%, mental health conditions at 25%, 20% for dementia and 20% for arthritis.

5. **Our gender balance is weighted towards female**

   Our Members are 60% female, 38% male and 2% other. We know that on average, men consult with their GP less than women between the ages of 16 and 60 years[4] so may be less likely to become involved.

6. **We have a mix of ethnicity within our Members**

   The profile of ethnicity amongst our Members shows a higher proportion of white when compared with the UK population. However, the profile of ethnicity in our Members is much closer to the profile of ethnicity of the "patient" population.[5]

7. **Our Members come from all parts of the UK**

   88% of our Members are from England. The population of England is 84% of the UK population[6].

8. **The weekly email round-up is being used by over 90% of Members[7]**

9. **Twitter[8] is used by 40% of our Members, but a quarter of those do not follow the use MY data Twitter account.**

10. **Our Members represent use MY data on many different groups across the UK.**

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[1] Members can identify as patients, carers and relatives, so the total will not necessarily add to 100%
[2] Members were able to identify as belonging to more than one disease area
[3] Relatives and carers were able to identify as belonging to more than one disease area
[4] https://bmjopen.bmj.com/content/3/8/e003320
[5] "The ethnicity of our Members", p15
[6] 88% of the 103 Members who responded to the census
[7] 90% of the 103 Members who responded to the census
[8] 40% of the 103 Members who responded to the census

What do we need to do next?

The standout area where more representation is needed is in health conditions other than cancer. To help the spread of Membership, we need Members across a wider range of disease areas and long-term conditions.

The Advisory Group and Secretariat have identified some initial actions and we are calling on our Members to assist.

Actions for the Secretariat

1. Engage with the National Institute for Health Research (NIHR) Dissemination and Engagement Centre, initially to promote the use of our data citation in all their publications (where relevant).

2. Work more closely with the Health Data Research Hubs' patient and public groups and seek to recruit all of their Members.

3. Run an external communications campaign, via an updated website and Twitter, to encourage recruitment. The timing for the recruitment by the Secretariat will need to be planned carefully with the recruitment activities for Members.

4. Produce a standard presentation slide deck for existing Members to use to aid recruitment of new Members. This will be added to the existing introductory package, available at www.usemydata.org.uk/joining.php

5. Approach selected charities for joint projects and outreach to their Members. This will be charities who have a strong research agenda that is not cancer. Initial suggestions from the Advisory Group are Parkinson's UK, Sickle Cell Society, MS Society and the Patients Association. Ask if their Members have any health data stories, which they would like to share with us, and if their Members wish to join us.

Actions for our Members

1. Please use all possible methods to promote the work of use MY data generally:
   - Please spread the word about use MY data to any other groups or networks you are involved with
   - If you use Twitter, please follow and engage with use MY data's account to help us promote our work - @useMYdata.

2. Aim to recruit one new member each, particularly from outside the area of cancer. This should be someone who has a patient data story to tell, or someone who has doubts or questions about the use of data and is interested in finding out about how health data is used.

   Send the introductory package to potential Members. This describes the work of use MY data and the benefits of joining. It is available and free to access here - www.usemydata.org.uk/joining.php

3. Identify opportunities for use MY data to work with organisations that cover disease areas other than cancer. This could be sharing events, inviting organisations to give presentations to use MY data Members and/or use MY data Members presenting to the organisations.

Please contact the Secretariat with information, suggestions and any follow-up questions you may have - secretariat@usemydata.org.uk.

Background to the Census

Since use MY data began it has grown organically and has always been open to Members from all backgrounds. We are a movement that concerns itself with inclusion and seeks to emphasise the voice of patients to understand aspirations and concerns around the use of data in delivery, service improvement, and in research.

As an open movement, we have never asked our Members to provide any details about themselves, such as age, ethnicity or gender. However, to help meet our aim we need to understand the breadth of our Members' experiences and backgrounds. We want to do this to understand whose voices are missing or under-represented. We will then be able to begin work to remedy this.

How we did the Census

Working with our Advisory Group, the Secretariat produced a census to collect this information from our Members. The first part of the census was about personal characteristics and the second part about engagement activities.

The census was anonymous and did not gather any information that could identify participants.

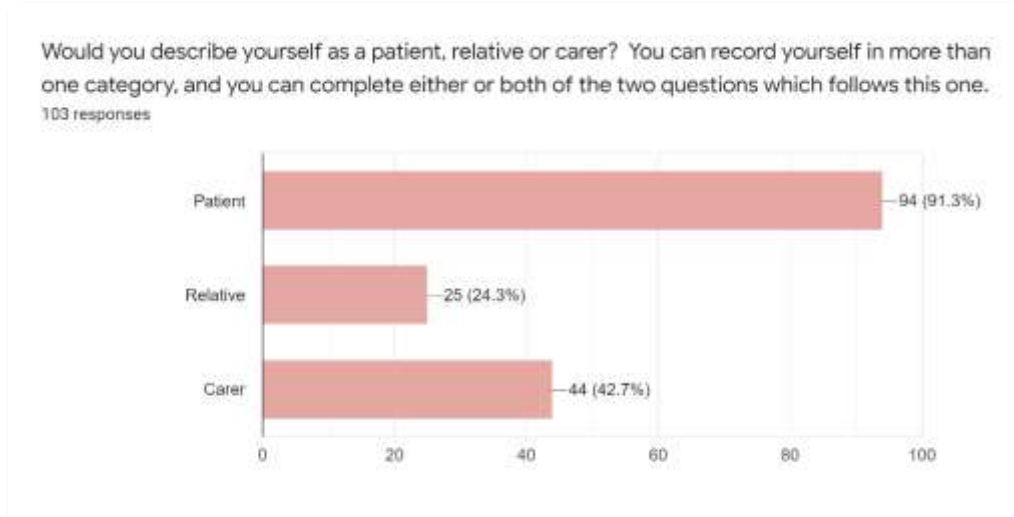The census ran from mid-July to early August 2020.

The questions we asked

1. Would you describe yourself as a patient, relative or carer? (Members could record themselves in more than one category)
    a. If you are a patient......Would you say that you have had, or have, a particular medical condition? (multiple selections)
    b. If you are a relative or carer......What medical conditions does (or did) your relative, or the person you were caring for, have? (multiple selections)
2. How would you describe your gender?
3. What is your ethnic group as a whole?
4. What age-group are you in?
5. If you have represented use MY data at other groups or meetings, it would be helpful if you could give some details.
6. Usage of Twitter
7. If you have accessed the use MY data website, what you accessed it for

The Census results in full

The mix of patients, relatives and carers in our Members

91% of Members classified themselves as patients, and 43% classified themselves as carers, and 24% as relatives

Would you describe yourself as a patient, relative or carer? You can record yourself in more than one category, and you can complete either or both of the two questions which follows this one.
103 responses

Patient	94 (91.3%)
Relative	25 (24.3%)
Carer	44 (42.7%)

Details of the health conditions amongst our patient Members

The census included a range of the most common conditions, allowing Members (who identified as being a patient) to record one or more of these conditions.

It was perhaps not surprising (given the background of use MY data) to see that 70% of Members reported themselves as being/have been a cancer patient.

But there was clearly a spread of conditions that our patient Members reported, showing that we have moved beyond our cancer roots. 25% of our patient Members have arthritis, over 10% report a mental health condition and over 10% a cardiovascular condition.

If we are become more representative of a wider patient/condition population, we need to seek out Members from a wider set of conditions.

The analysis of the conditions which were included in the Census question is:

Patient conditions	Percentage
Cancer	70%
Arthritis	22%
A mental health condition	10%
Diabetes	6%
Stroke	5%
Coronary heart disease	4%
Dementia	1%

However, we allowed Members to include any other conditions which they wanted to note. Analysis of these results highlighted that our patient Members reported around 30 separate conditions. A fuller list is shown below:

Other reported conditions (A-Z)

Amputation
Asthma
Bronchiectasis
Cataracts
CFS
Chronic cellulitis and venous degeneration
Chronic migraine
COPD
COVID-19
Deafness
Epilepsy
Fibromyalgia
Guillain Barre
Gynae condition
Haemochromatosis
Hypertension
Kidney Problems
Lung disease
Muscular dystrophy
Neurological condition
Osteoarthritis
Osteopenia
Osteoporosis
Propriospinal myoclonus
Radiation proctitis
Severe respiratory disease
Skin disorder
SLE
Spinal Stenosis

Details of the health conditions for the person being cared for

There was a very different spread of health conditions for the person being cared for. Just over 40% of our patient Members reported that they were also a relative or carer.

Around 10% of our Members are not patients, reporting either as relatives or carers.

Around half our Members identified just as patients.

In terms of the breakdown of conditions for those being cared for, cancer was over 75%, but cardiovascular conditions were over 25%, mental health conditions at 28%, and nearly 20% for dementia and arthritis.

Condition of the patient connected to the relative/carer	Percentage
Cancer	76%
A mental health condition	28%
Diabetes	19%
Dementia	19%
Coronary heart disease	16%
Arthritis	14%
Stroke	9%

Other reported conditions (A-Z)
ASD/ADHD
Bronchiectasis
Dementia
Emphysema
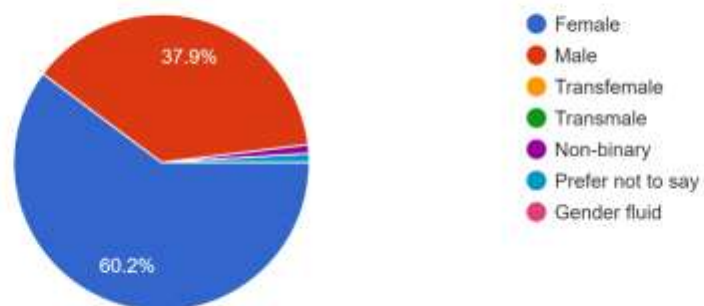Epilepsy
Multiple Sclerosis

The gender balance of our Members

Our Members are 60% female, 38% male and 2% other.

According to official statistics, the proportion of the UK population who define as non-binary when given a choice between male, female and another option is 0.4% (Titman, 2014).

How would you describe your gender?

103 responses
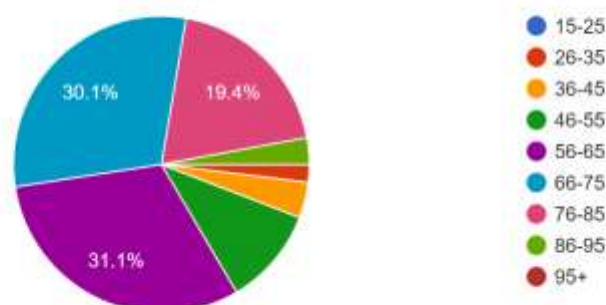
The age profile of our Members

As might be expected for a patient movement, we have limited representation in the younger age groups. No Members reported being younger than the 26-35 age group.

The age-group figures are shown in the following table and chart:

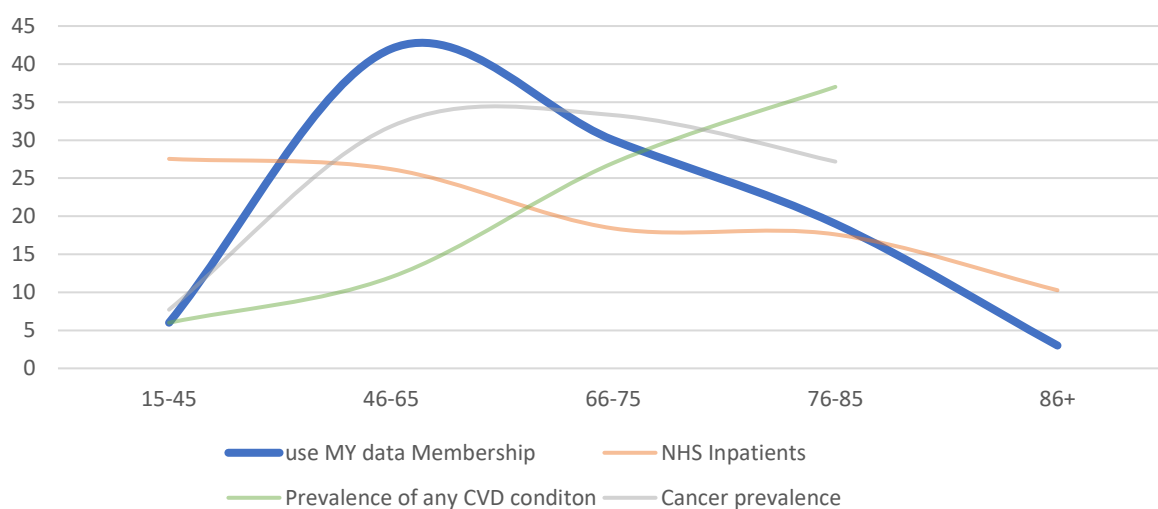| Age group	Percentage (rounded)
15-25	
26-35	2%
36-45	4%
46-55	11%
56-65	31%
66-75	30%
76-85	19%
86-95	3%
95+	

What age-group are you in?
103 responses

Given that we a patient-focused population, it may be fairer to compare the age profile of our Membership with the age profile of "patients". We have done this by using different a comparison of the number of age-profile of hospital inpatients in England for a year, and also the age-profile of the latest published figures for cancer prevalence.

Clearly, neither of these measures provides a perfect answer, but the age-profile comparison between use MY data Members with the two "patient" profiles is much closer than the age-profile of the population in general.

Membership age profile compared with age profiles of Inpatients, cancer prevalence, CVD prevalence

Legend:
- use MY data Membership
- NHS Inpatients
- Prevalence of any CVD conditon
- Cancer prevalence

X-axis: 15-45, 46-65, 66-75, 76-85, 86+

Where our Members live

Our Members live in all parts of the UK, with by far the largest being from England. However, compared with the distribution of the UK population, our Members are relatively representative of the UK, as shown in the table and the chart below:

Country	Population (as a % of the UK)	Proportion (of Members)
England	84%	88%
Scotland	8%	5%
Wales	5%	3%
Northern Ireland	3%	4%

Where do you live?
103 responses
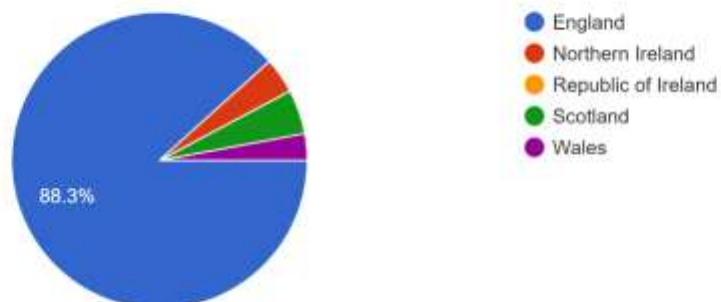
The ethnicity of our Members

We have a mix of ethnicity within our Members.

Using a very broad view, Members show as 91% from white ethnic groups and 9% from non-white ethnic groups. In contrast, the latest ONS Census figures from 2011 show that 86% of the population were from white ethnic groups.

ONS also highlighted that between 2001 and 2011 the population of smaller ethnic groups grew substantially. If we surmise that similar increases in the smaller ethnic groups have occurred between 2011 and 2020 in the population, then it is likely that the mix of ethnicity amongst our Members is not representative of the population (the "public") as a whole.

We also looked at comparisons with a "patient" population.

Given that we are a movement focused on patient data, it is useful to think about how the composition of our Members compares with the part of the population that are most likely to use healthcare services more intensively, or more likely to be "patients".

We considered people over 40 as being the more intensive users of the healthcare system, and statistically more likely to be "patients".

Clearly, the over 40 cut-off ignores earlier life-events such as pregnancy, and chronic conditions which may be detected in earlier years. Nevertheless, as disease increases significantly with age, it is not unreasonable for these purposes to argue that this is more reflective of the "patient" population, and can provide a useful comparator of the ethnic mix of those in the "patient" cohort and that of our Members.

When looking at the over-40s in the population (from the 2011 ONS Census), the ethnic mix highlights that for all "non-white" populations combined there is a dramatically lower proportion over the age of 40. In fact, for the over 40s, 92% of the population are within the White ethnic groups.

This 92%/8% (white/non-white) figure is much closer to the overall composition of our Members.

In terms of the ethnic diversity reported by our Members, the charts below show that whilst the numbers are small, we do have a mix of representation from smaller ethnic groups. We did not have any Members reporting in the Arab ethnic group.

What is your ethnic group as a whole? (The grouping is taken from the 2011 ONS Household Survey, plus reflects updated Government guidance at https://www.ethnicity-facts-figures.service.gov.uk/style-guide/writing-about)
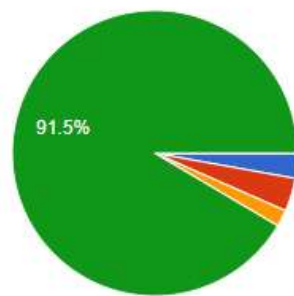
106 responses

- Asian / Asian British
- Black / African / Caribbean / Black British
- Mixed / Multiple ethnic groups
- White
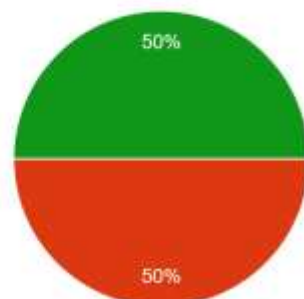- Other ethnic group

91.5%

White

93 responses
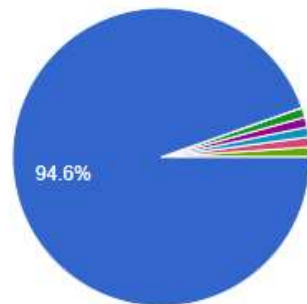
- English/Welsh/Scottish/Northern Irish/ British
- Irish
- Gypsy or Irish Traveller
- Caucasion
- European
- French
- French/Russian/English/ Irish
- Middle European
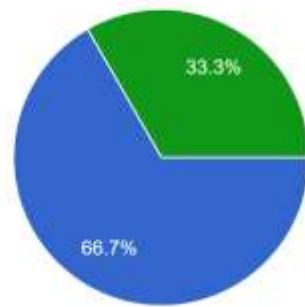
94.6%

Mixed / multiple ethnic groups

2 responses

- White and Black Caribbean
- White and Black African
- White and Asian
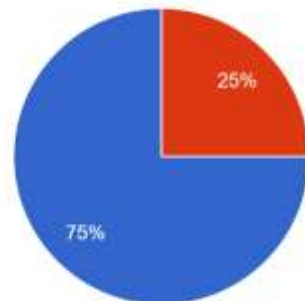- White and Middle Eastern

50%

50%

Asian / Asian British

3 responses

- ● Indian
- ● Pakistani
- ● Bangladeshi
- ● Chinese

33.3%

66.7%

Black/African/Caribbean/Black British

4 responses

- ● African
- ● Caribbean

25%

75%

Digital communications and our Members

The weekly email round-up is being used by over 90% of the Members who responded to the Census. We receive regular feedback that the round-up (often called a newsletter) is seen as a very useful form of communication.

We use Twitter actively as a rapid form of engagement, and in particular to reach a much wider network. However, only 40% of Census respondents use Twitter, and a quarter of those don't actually follow use MY data.

Where do our Members represent use MY data?

Our Members represent use MY data on many different groups across the UK. We allowed a free-text entry for Members to indicate which groups they attended for use MY data. The table of results is shown below in alphabetical order:

Details of Group or Event (A – Z)
European Parliament and European Commission on GDPR
Formerly Cancer Partnership Group East Sussex. Now lapsed due to cutbacks
Genetics Advisory Group
Great Ormond Street Hospital (GOSH)
HDR UK
Highlighted the importance of using the Patient Data Citation to Members of the NCRI Haematological Oncology Group (formerly the Clinical Studies Group)
Highlighted the importance of using the Patient Data Citation to Members of the NCRI Acute Lymphoblastic Leukaemia Subgroup
Highlighting the Citation during a presentation at the Haem Onc Annual Clinical Trials Day.
Independent Cancer Patients Voice (ICPV)
Issue with Tissue
MP meeting
National Cancer Registration and Analysis Service : Britain Against Cancer
NDG Oversight Group for Public Dialogue about Public Benefit
Others too but I can't recall details.
Public event panel member: webinar panel member
Research use of data
Several, can't be specific.
Sit on various Data vetting panels as a useMYdata Rep
The Issue with Tissue Consultation
Too many to list
Various organisations