

# Representativeness of the Adult Social Care Surveys

**NIHR SSCR Webinar Series**

Tuesday May 11<sup>th</sup> 2021

# Disclaimer

This study is funded by the National Institute for Health Research (NIHR) Policy Research Programme (PRP) under grant NIHR200692. The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

## Use of this presentation

This presentation is provided only for use during the NIHR SSCR Webinar on May 11th.

## Published results

<https://www.ipsos.com/ipsos-mori/en-uk/representativeness-adult-social-care-surveys>

# Aims and approach

# Aims and objectives

- Review the **representativeness** of the ASCS and SACE, and the reasons for any disparities.
- Identify ways in which the **views of under-represented groups could be captured** by local authorities by:
  - reviewing the current methodology; and
  - exploring other examples of best practice.
- Identify ways in which the surveys could be **enhanced** by using recent developments and innovations in survey methodology.
- Provide recommendations which will facilitate **improvements** in the surveys.

# Methodology



## Review of methodology

To understand **how surveys are administered** and related to literature



## Stakeholder consultation

1. **Online feedback exercise with LAs**: it was sent to the Adult Social Care Director in every LA in England and to NHS digital contacts. 94 people responded incl. 74 of those had an analytical role in their LA.
2. **In depth interviews with LAs** (x14)
3. **Interviews with non-LA stakeholders** (x15)



## Literature review of best practice

For gathering data from **people with high needs** for survey methodology



## Secondary Analysis

Secondary analysis of the **sample and population data** to understand representativeness



## Users and carers involvement

**10 in-depth interviews** (six service users and four carers)

# Representativeness of the surveys

# Defining the eligible population

## ASCS

Users in receipt of long-term support services funded or managed by the council following a full assessment of need

## SACE

Adult carers caring for adults on LA records whether or not there has been a review or assessment in last 12 months

### Some groups currently excluded from the sample including:

- short-term users
- users receiving other forms of support from the local authority (e.g. signposting, equipment, mental health support)
- users self-funding their care
- carers who are not in touch with the local authority
- young carers

### Since the survey started:

- Care Act 2014: Wellbeing, prevention
- Strength based approaches to support

## Eligible population exclusions from the survey

### ASCS

Those lacking mental capacity, in hospital, in a safeguarding or other dispute and other reasons

### SACE

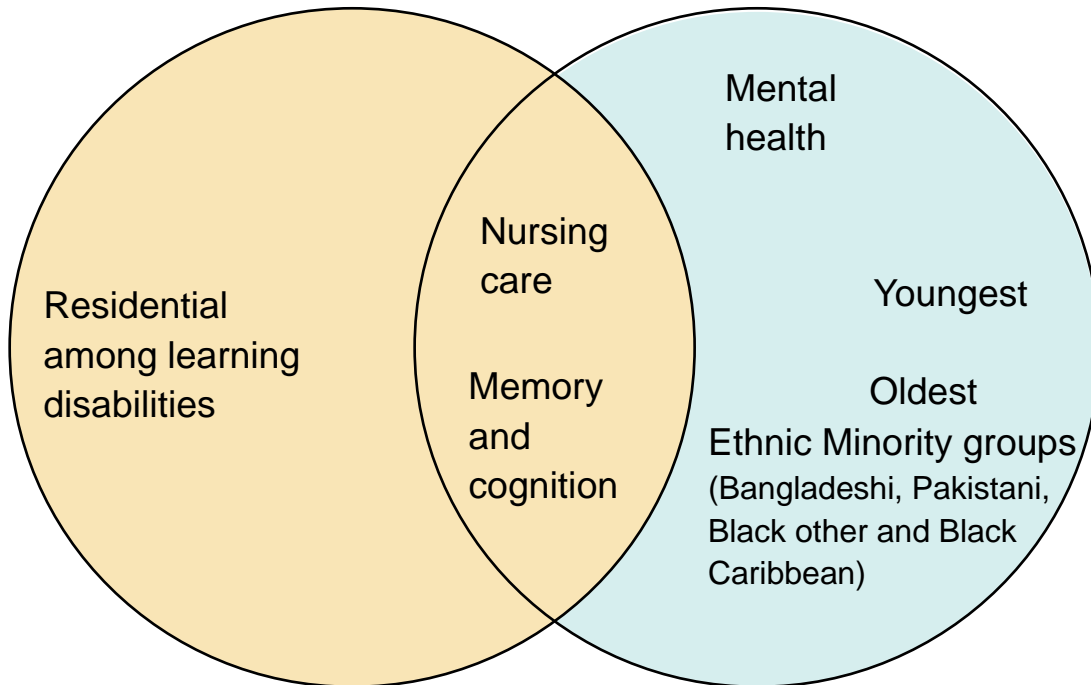
Those in residential care, in hospital, in a safeguarding or other dispute, person they care for has died etc

# Summary of under-representation

## ASCS

Issued sample

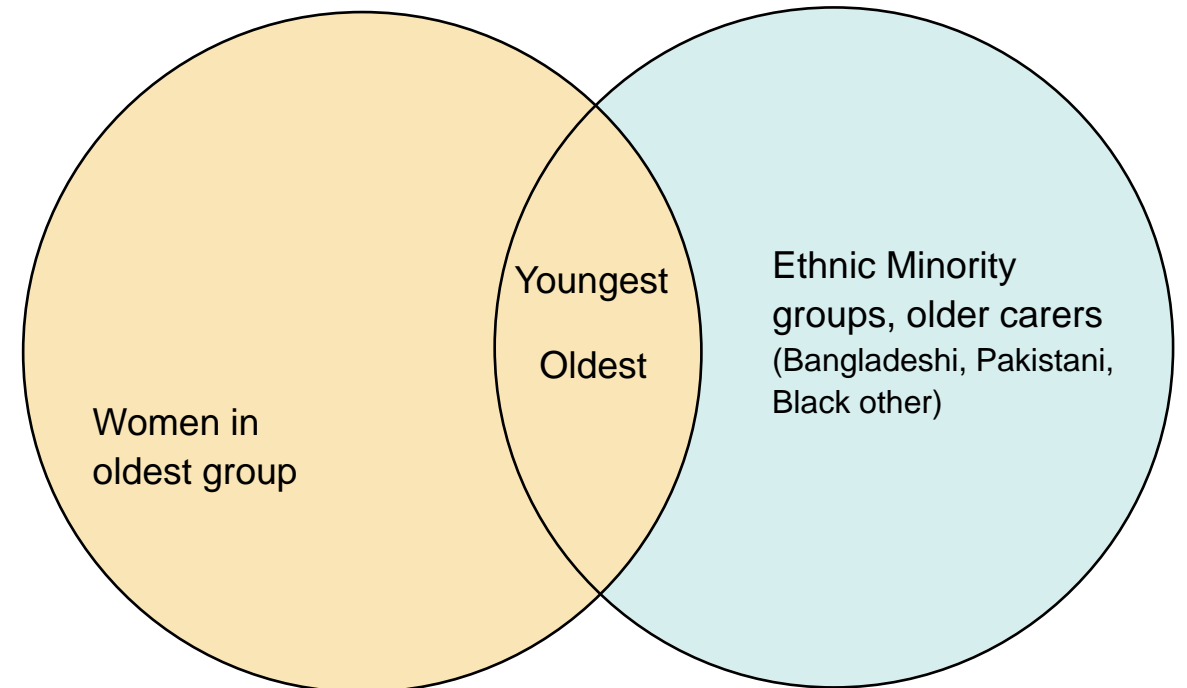
Response



## SACE

Issued sample

Response

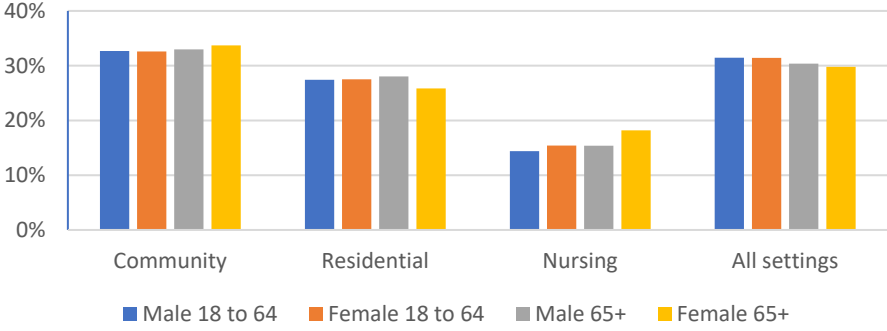




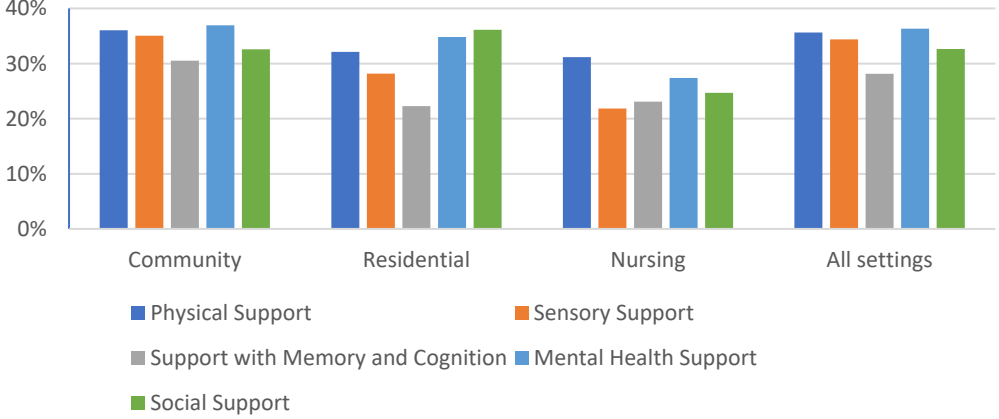
# ASCS: Percentage of eligible population issued varies by setting and need

## Lowest in nursing settings and those with memory and cognition support needs

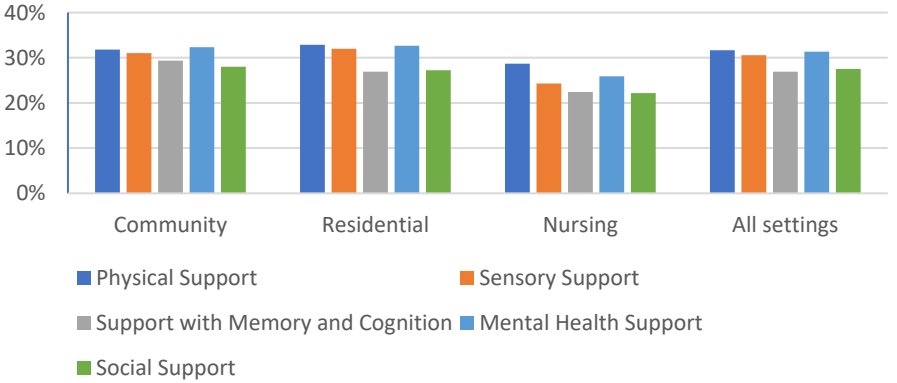
ASCS: Learning disability - percentage of eligible population issued by setting, gender, age (Stratum 1) (2015-19 combined)



ASCS: Aged 18-64 - percentage of eligible population issued by setting and primary support reason (Stratum 2) (2015-19 combined)



ASCS: Aged 65 and over - percentage of eligible population issued by setting and primary support reason (Stratum 3 and 4) (2015-19 combined)



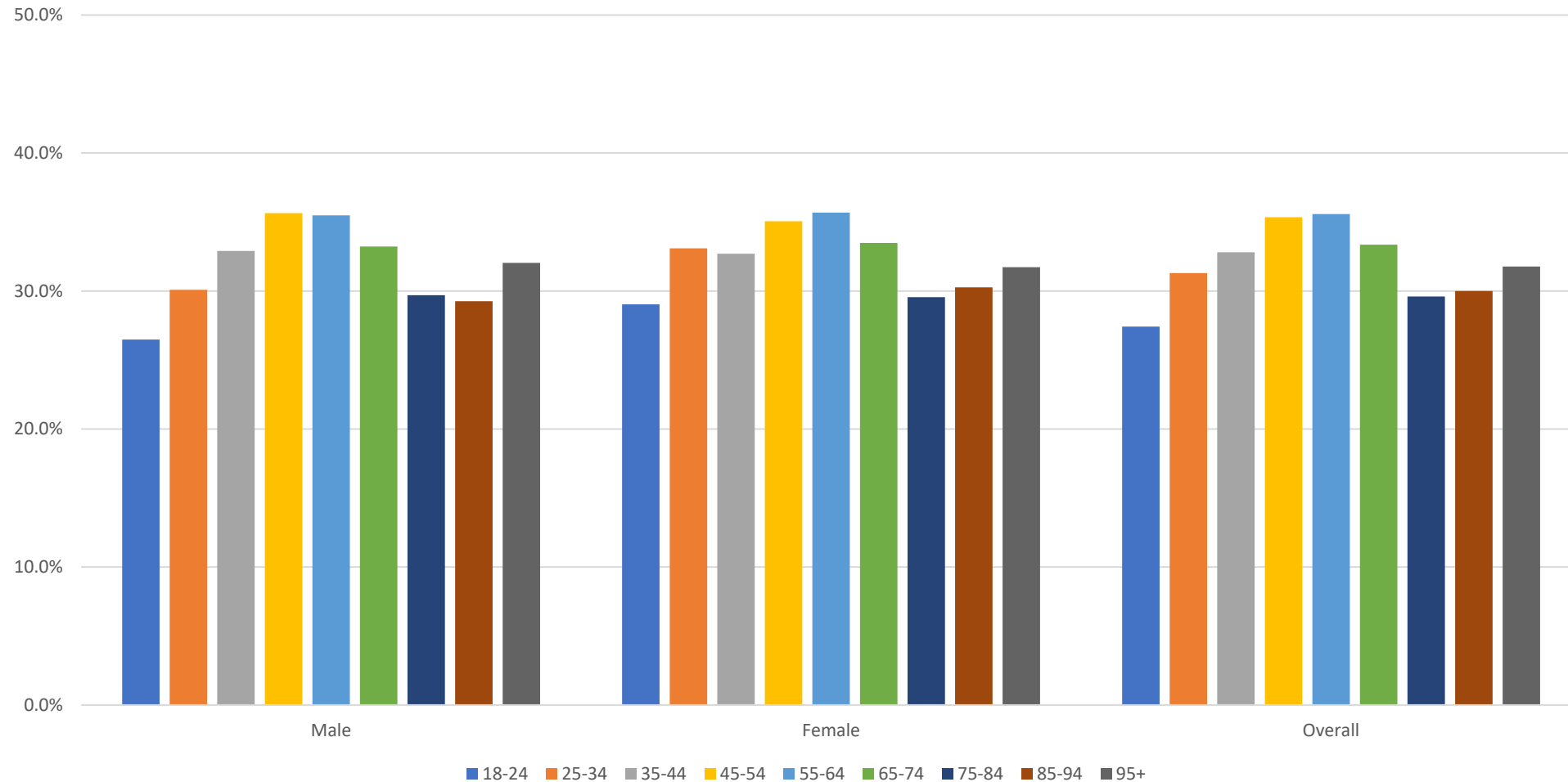
### Survey stratum for issued sample:

1. learning disability
2. non-learning disability aged 18-64
3. non-learning disability aged 65+ in residential or nursing care
4. non-learning disability aged 65+ using community based services

# ASCS: Response rates vary by age but not by gender

## Lowest in youngest and older groups

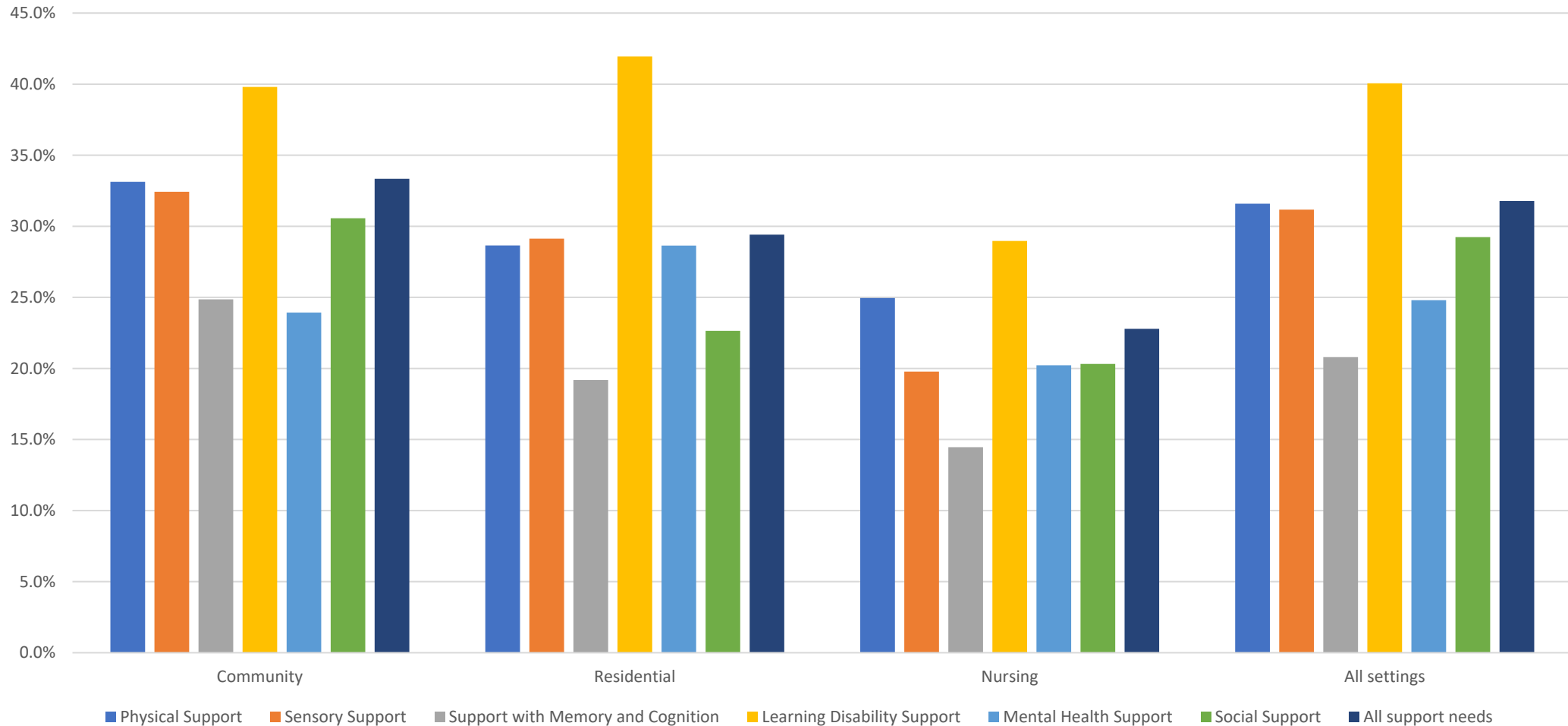
ASCS: Response rate by age and gender (2018-19)



# ASCS: Response rates vary by setting and need

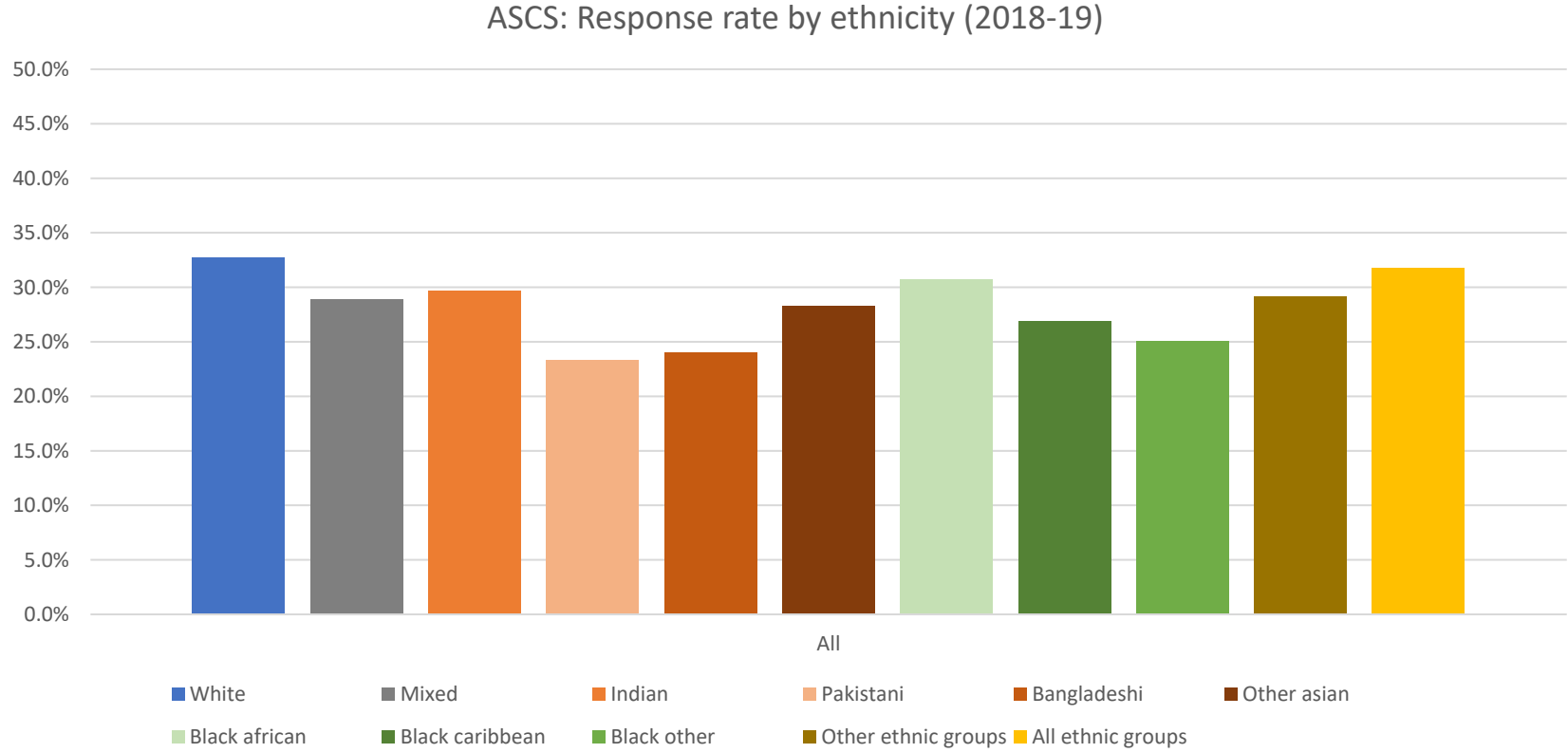
## Those in nursing care and with memory and cognition needs have lowest response

ASCS: Response rate by setting and primary support need (2018-19)



# ASCS: Response rates vary by ethnicity, overall and within broad groups

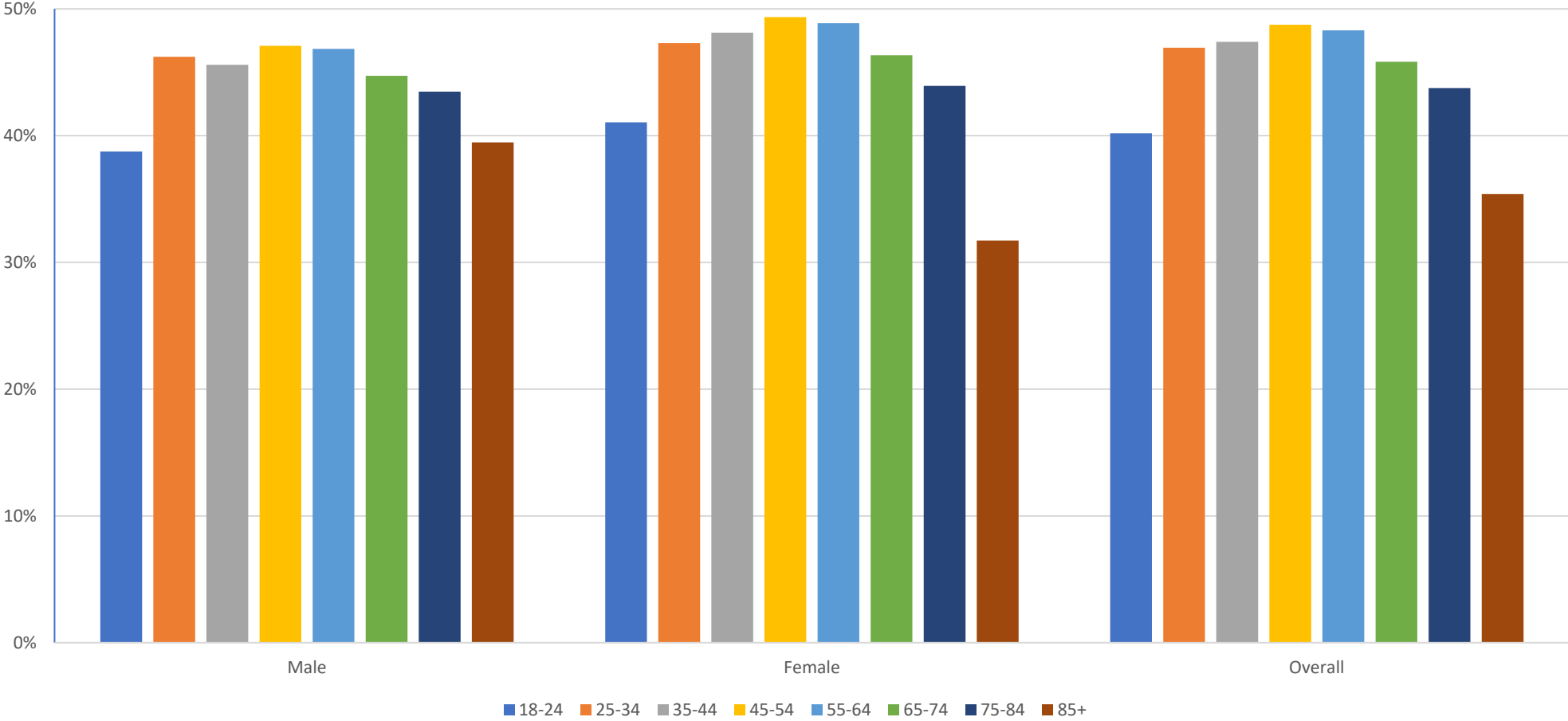
Highest in White group and lowest in Pakistani, Bangladeshi and Black Other  
Same pattern in all age groups



# SACE: Percentage of eligible population issued varies by age but not gender

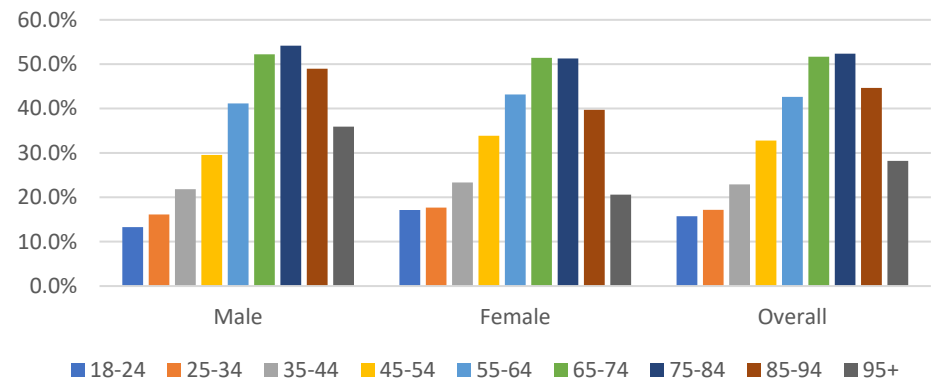
## Lowest in youngest and oldest groups

SACE: Percentage of eligible population issued by age and gender (2018-19)



# SACE: Response rates vary by age and ethnicity

SACE: Response rate by age and gender (2018-2019)

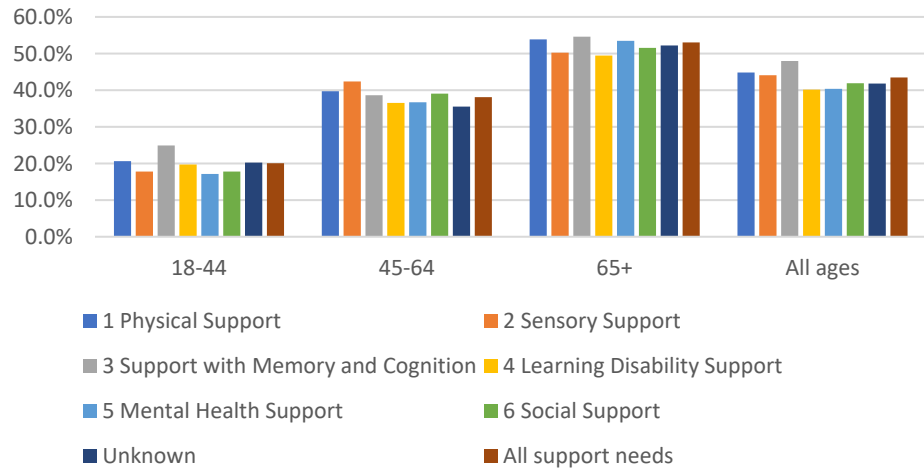


Lowest in youngest and very oldest

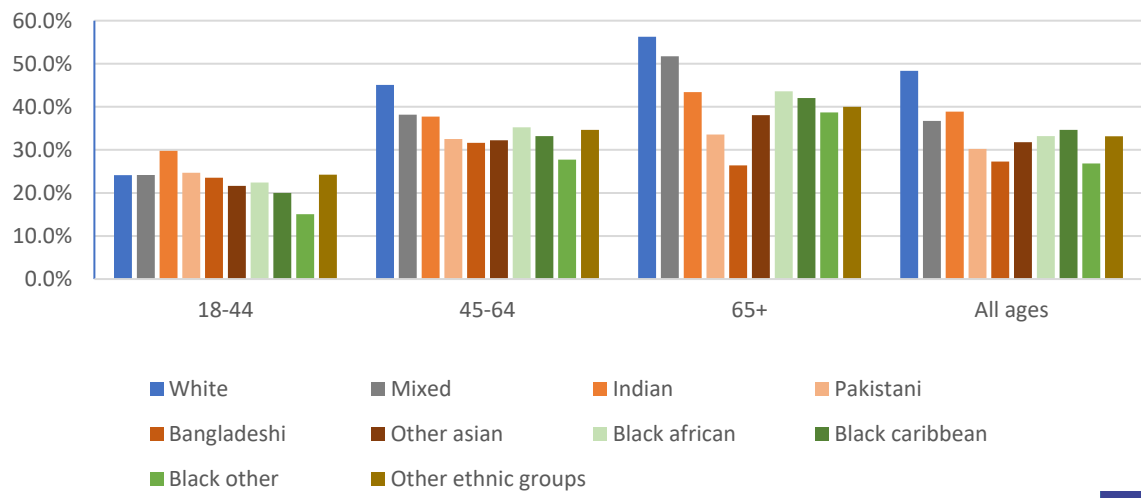
Little gender difference except among oldest

Ethnic variation is mainly found in older people

SACE: Response rate by age and Primary support reason for cared for person (2016-2019)



SACE: Response rate by ethnicity and age (2016-19)



# Eligible population and sample



# Challenges with the eligible population records

## ASCS

LAs feel that the **data quality** for service users on the **SALT return** is generally good. A lot of work is needed to ensure the details are accurate and usable for the sample.

## SACE

Carers' records are **not as complete and accurate** as the ones of service users:

- Carers' details are not always recorded in their own right.
- Some carers' organisations and networks might be reluctant to share contact details.
- Definition of eligible carer is not clear-cut; LAs have to interpret this themselves.



# Local authorities have difficulty engaging care homes in the task of assessing mental capacity

## Contacting care homes

- Local Authorities use a **range of practices** to contact care homes before the ASCS is mailed out (letter, phone, email).
- But **engagement** from care homes on mental capacity checks varies but **tends to be low**.

## Assessing mental capacity

- Local Authorities do not know **how capacity is determined by care homes**.
- They feel care homes can be **too strict** when they assess capacity where is it determined.
- Capacity can be hard to assess when it **fluctuates**.
- In many cases capacity is not determined at the **initial stage** of contacting homes.

Only half of LAs feel care homes are successful in excluding those who lack mental capacity

- LAs feel the survey is **not seen as a priority** by care homes.
- LAs understand the **pressures** faced by care homes.
- As a result questionnaires get sent out to people who lack mental capacity.

*We've noticed over the years that the surveys would go to the care homes, they hit the reception, and the default would almost be, 'Well, sorry, these people in these homes haven't got the capacity to answer the survey.' So, we weren't allowed to survey them, in principle. (Local Authority)*

# **Barriers to participation**

## **identified by LAs, service users and carers**

# Barriers to participation relevant to specific groups- 1

## Those with dementia and cognitive decline

- 63 per cent of LAs concerned that this group is under-represented in the ASCS
- Low response among those who are invited as those lacking capacity are invited
- Difficulties in completing the paper questionnaires, due to mental capacity or visual impairments
- Accessible formats such as adapted easy read versions may improve response rates
- Facilitated face-to-face interviews or help from advocates can help
- Proxy response may be needed for some

## Service users living in residential care homes

- Staff in care homes may act as gatekeepers:
  - Concern about monitoring of individual care homes
  - Judgements based on condition rather than capacity
- Help from staff may bias the feedback provided
- Tension between encouraging response and enabling service users to respond

## Learning disability service users

- Well represented in the ASCS
- Receive targeted easy read questionnaire
- Levels of satisfaction higher than any others for a variety of reasons
- While the easy read questionnaire increases accessibility, there is concern over how appropriate it is
- Where carer responds on their behalf certain questions are challenging to answer, proxy questionnaire may be easier

# Barriers to participation relevant to specific groups- 2

## Ethnic minority groups

- LAs do not collect consistent information about the languages their service users speak
- LAs are reliant on service users reading the translation sheet and requesting translated versions
- Language issues are not the only barriers for ethnic minority groups
- Lack of trust and engagement, concern about impacts, lack of understanding of value

## Mental health service users

- Where mental health services are not provided by the Adult Social Care Service, service users may not understand why they are receiving the survey and therefore not complete it
- Mental health services may not provide local authorities with service users' contact details
- Mental health service users are in a group often considered as more difficult to engage in research

## Carers, especially younger

- Carers do not always recognise SACE is relevant to them
- Carers face multiple pressures and responsibilities
- Response rates among younger carers may increase if other modes are used to collect feedback - such as online approaches

# There are a number of barriers to participation relevant among all groups of service users and carers

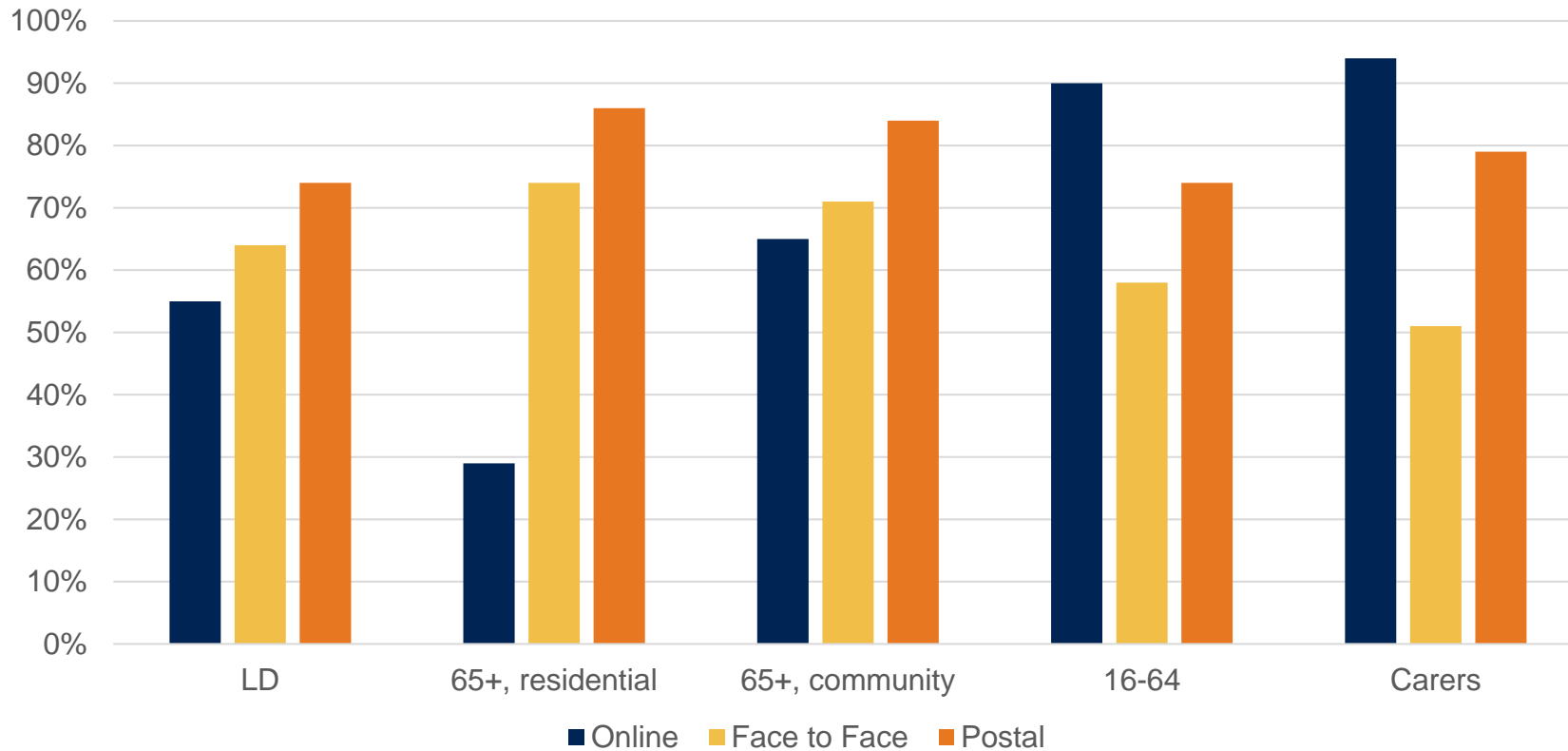
- There are **differing understandings of the purpose of the ASCS and SACE** among users and carers.
- Some participants felt that the responses they provided **could impact on the services** they as an individual would receive. This could include positive or negative impacts.
- **Survey burden** may prevent carers from completing the SACE.

*(when you are a carer), you have to repeat yourself a lot, whether it is for disability benefits, forms, surveys, personal benefits, universal credit, other forms, carers allowance. We are consistently filling forms and consistently repeating ourselves so a survey that you don't have to do will probably also put people off as we are constant form fillers as carers (Carer)*

# **Facilitators to participation identified by LAs, service users and carers**

# LAs felt a combination of methodologies are required to successfully obtain feedback across different groups of users and carers

Which methods would be successful at obtaining feedback?



Though in in-depth interviews they told us...

- Face-to-Face would be expensive and unfeasible given the constraints on resources within councils
- Online offers accessibility and efficiency advantages
- Mode effects

Q18 Which of the following types of survey do you think would be appropriate for obtaining feedback from service users and carers in your local authority? Please think generally, ignoring cost or resource implications. Base:86

# Other innovations

## Proxy survey:

- A proxy survey could be low-cost means for **including the voices** of those who lack capacity.
- But difficult to **target proxy** respondents and **ethical considerations** around consent.
- **Whose perspective** is the proxy respondent being asked to provide and **potential for bias**.
- The importance of **clear rules** for whom should act as a proxy would be needed: care and support workers and carers introduce different biases.

## Qualitative methods:

- More information is needed to fully understand and act on the survey findings.
- **An option rather than a required part** of the protocol.
- The addition of a **comments box** would help but need clarity for participants on how it would be used.



# Some facilitators to participation were also identified by users and carers

- Overall, service users and carers are keen to give feedback on the services they receive but:
  - would be motivated to take part by **financial or other incentives**
  - think the content of the **invitation letters**, while comprehensive, may not be accessible to all
- Service users would prefer a **family member or friend** to answer the ASCS on their behalf, rather than a care and support worker.
- Opportunities to give feedback on their services should be considered **outside the surveys**.

*"I always tell people they need to always consider, when filling out information, what your worst days are, you need to be able to give a range of experiences. Some people are proud and don't want support or help and will answer differently." (Service user)*

# Key learnings and recommendations



# Summary of recommendations

Consider how any changes impact on benchmarking, hearing voices of users and carers, understanding issues and improving services.

## Eligible population and sample

Explore ways of reaching non-eligible population

Improve records – organisation, consistency, content

Record sharing and GDPR

How to hear from those who cannot consent

## Research tools

Easy read development

Targeting translations

Online approaches

Telephone and face to face

Qualitative methods

## Support to take part

Carers

Proxies

Advocates

But consider bias

## Engagement

Involve under-represented groups

Engage with community organisations

Engage with care homes and providers

Use cover letter to engage with participants:

- relevance to them
- how taking part makes a difference

Introduction of comments box

Other feedback methods

## Survey organisation

Frequency

Centralisation v local organisation

Impact of updated client level SALT

Efficiency and standardisation v local use

Sharing of experience and good practice among LAs

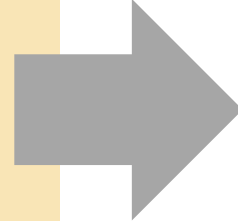
Share evidence about under-representation

Use of incentives

# Defining the eligible population

## Key learnings

- **Short-term users** can be identified from LA records but there are other challenges to their inclusion in the survey.

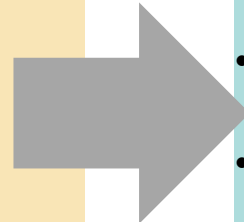


## Recommendations

- revisit short-term user ASCS questionnaire and cognitive testing report
- integrate with questions already being asked in LAs
- work with LAs to develop a sampling protocol e.g. census on completion of package or run at set times (quarterly or every 3 months)

## Key learning

- There are **groups who are excluded from the surveys** altogether or
- whose numbers in the eligible populations are too small for surveys' results to be meaningful at LA level



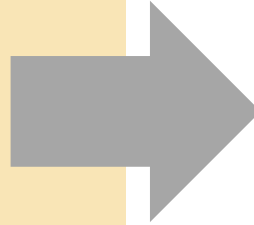
## Recommendations

- Recognise the variety of ways in which needs are met
- use of wider surveys of residents for those excluded from samples
- develop **qualitative research tools** to understand the views of small subgroups or important groups excluded from the research

# Creating the samples

## Key learnings

- Maintaining **accurate data** about the eligible populations as currently defined is challenging, especially for carers
- **Exclusions** from the ASCS and SACE sample frames are not always applied consistently




## Recommendations for NHS Digital

- work with LAs to bring **greater consistency to the data** held on service users and carers
- ensure that the requirement for client level data flows for the SALT return from 2021-22 aligns with the **information needs** for the ASCS and SACE
- Support LAs to overcome difficulties presented by sharing data between organisations under **GDPR legislation**
- provide more detailed guidance about the **exclusions** from the sample frame
- provide additional guidance and examples on the **definition of carers**
- Improve the collection of email and telephone if online modes are to be used

# Service users lacking mental capacity

## Key learnings

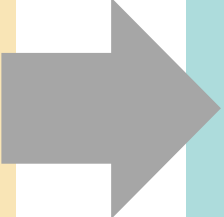
Excluding those lacking mental capacity to consent from the ASCS sample is **challenging** for local authorities



## Recommendations

- allow **time** for the mental capacity checks
- encourage LAs to **engage with care homes** face-to-face or by telephone
- LAs should not use the survey to **assess the performance** of individual care homes.
- provide more detail to LAs and care homes on **assessing mental capacity** - including standard example questions
- engage with **umbrella bodies, providers and care homes**
- any change to this process should link to options offered for assisting with completion

The views and experiences of this key group of service users **are being missed or captured in inconsistent ways**

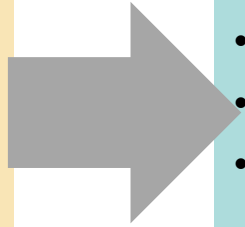


- encourage **qualified advocate** to assist users with completion
- consider **alternative formats**
- review and integrate the developments of the **proxy version of ASCOT**
- consider how family members or carers could act as consultee for service user
- update the cover letter and questionnaire to clarify the role of carers in completion

# Tools for data collection

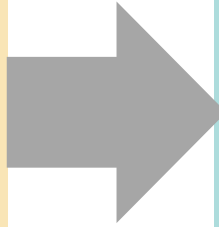
## Key learnings

The effectiveness and use of the **easy read version** of the questionnaire could improved



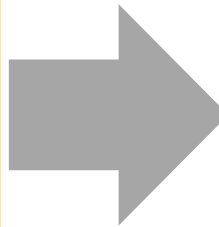
- consider how **updated easy read version of ASCOT** can be adopted in the ASCS
- develop a separate adapted easy read version suitable for those with **cognitive decline**
- easy read version must be **printed in colour or adapted to be black and white**
- understand the range of **appropriate formats** for people with different needs

**Translated questionnaires** are not well-used on the surveys and do not address all the issues faced by ethnic minority groups



- ensure that **preferred language** for communication is recorded
- send the **appropriate translated questionnaire** with the initial mailing
- require that the **translation request form** is placed upfront in the invitation package
- review the language questionnaires with service users and carers and groups
- if an online version of the questionnaire is offered, ensure that translations are built into this
- tackle wider barriers to participation among ethnic minority groups

**Face-to-face and telephone versions** are offered but not used consistently

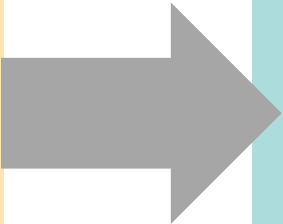


- carry out a **systematic pilot** of using face-to-face approaches in care homes
- explore role for **independent third-party organisations** with the advocacy skills
- broaden the circumstances in which **face-to-face or telephone** approaches can be used

# Online surveys

## Key learning

A **flexible online approach** offers potential for both surveys, particularly SACE



## Recommendations

- pilot of online approaches on the SACE should be **future focussed**
- a pilot should consider the way people respond on **different devices**
- a flexible online approach is recommended with **push-to-web** for some groups and a **sequential mixed mode** for other groups
- the online versions should take **advantage of flexibility** e.g. targeting translations, easy read versions and proxy versions
- ensure that any developments to the questionnaire resulting from other parallel work are designed to be **unimodal** and suitable for online, paper, face-to-face or telephone
- ensure that any updates to the standard information is designed to **facilitate future online surveys (e.g. gather emails and consent to use them)**

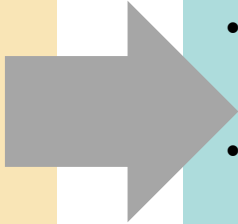


# Means of encouraging participation

## Key learnings

The annual nature of the ASCS and the finite population of service users means **survey fatigue can be an issue**

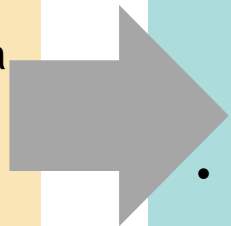
**The wide definition of carers** means not all recognise it as relevant



## Recommendations

- adapt and re-arrange the survey **cover letters**
- show service users and carers **how taking part will make a difference**
- show service users and carers why it is **relevant to them**
- add a **comments box** to the questionnaire to enable people to provide any qualitative feedback they may wish to
- consider whether any of the survey content could be removed to **reduce the length** and burden on participants, and consider whether rearranging could make it look shorter
- remind LAs of the benefits of including a questionnaire with the **reminder letter**
- **learn from and share** the experience of LAs on what works well in practice
- consider the **introduction of incentives** on the survey

**Community groups and advocates** have a potential role to play among under-represented groups



- engage with a range of local and national **community, faith and support groups** to support participation and raise awareness of the survey
- involve these groups in design, development and use of the survey
- provide LAs with materials and ideas to assist them **in promoting the surveys** to the wider community and with particular groups
- guidance on how **advocates** can support service users and carers in completion

# To conclude...

- In making decisions about next steps, **the recommendations need to be considered as a whole**, and in the light of recommendations from other recent reviews.
- While there are recommendations which directly address the issue of under-representativeness, some may have both **positive and negative impacts on representativeness**.
- There is **enormous commitment** to these surveys, and to adult social care statistics generally, among local authorities and a wide range of stakeholders and any changes resulting from these recommendations should be **developed in partnership**.
- There are no quick fixes, but a variety of **tools and approaches** can be used to improve representativeness while having wider benefits for data quality and the value of the surveys to local authorities.

# Reports

- <https://www.ipsos.com/ipsos-mori/en-uk/representativeness-adult-social-care-surveys>
- Main report of findings
  - Secondary analysis annex
  - Methodology annex
  - Research materials
- Methodology review
- Literature review

# Thank you.

Margaret Blake  
Camille Aznar

Ipsos MORI



# Who did we talk to?

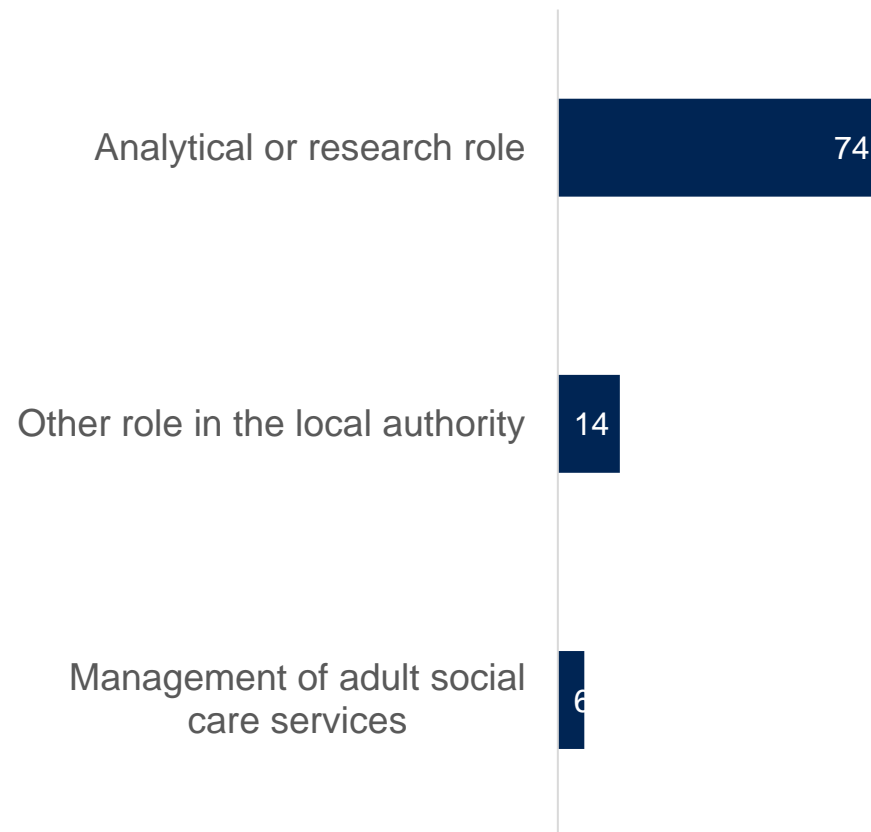
**LA survey:** The online survey was sent to the Adult Social Care Director in every local authority in England and to NHS digital contacts. 94 people responded to the survey, 74 of those had an analytical role in their LA. 80 completed the whole survey. 12 LAs had responses from two people.

**LA interviews:** We then conducted 14 in-depth interviews with respondents of the survey to explore their answers in more detail.

**Non-LA stakeholder interviews:** We also conducted 15 in-depth interviews with a range of stakeholders around the representativeness of the surveys and the suitability of the survey methodology.

**Service users and carers interviews :** we carried out ten in-depth telephone interviews with six service users and four carers to explore the experiences of taking part in research about satisfaction with social care.

What is your main role in the local authority? (Survey)



Q1, What is your main role in the local authority? Base: 94 (multicode)