

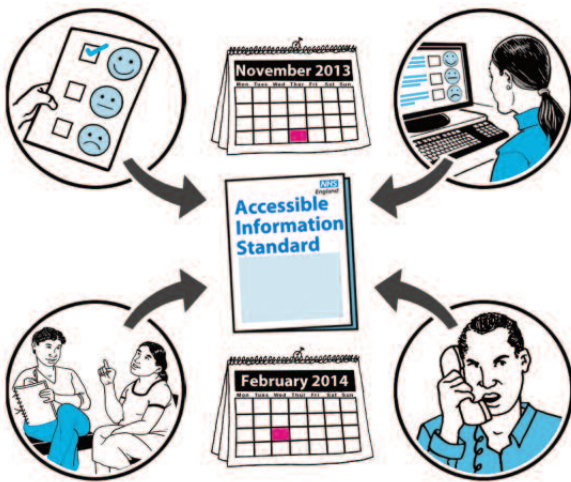


# Easy read report of engagement activity

**Making health and social care information accessible**

November 2013 - February 2014

# 1 Executive Summary



From mid-November 2013 until 21 February 2014 NHS England invited the views of people to help develop a new accessible information standard.

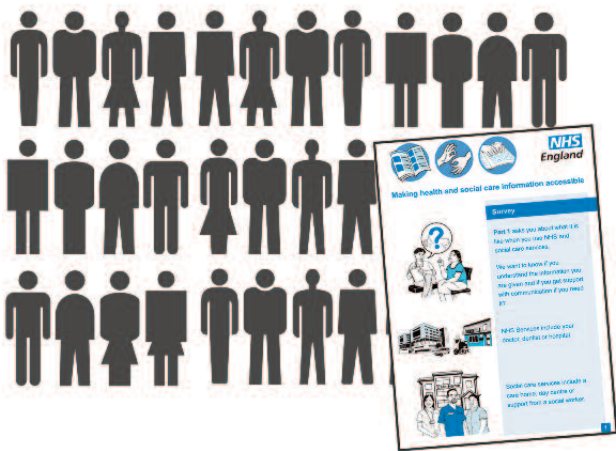
The project is called **Making health and social care information accessible.**



A range of individuals, groups and organisations were able to share their experiences and put forward suggestions for improvements in accessible information and communication support.



A series of workshops were also held, in partnership with national charities, to seek views from patient groups.



During the three month period, **1,147** completed surveys (questionnaires) were received, and over **150 people** participated in face-to-face workshops.

## 2 Thank you



NHS England would like to thank all of the individuals, groups and organisations that supported the engagement.





We are really grateful to those who supported people to complete the surveys.



And to those voluntary organisations and self-advocacy groups who supported people to have their say as part of workshops or meetings.



Thanks are also due to all those who promoted the online surveys or workshops on their websites, blogs or social media accounts.

# 3 Communications



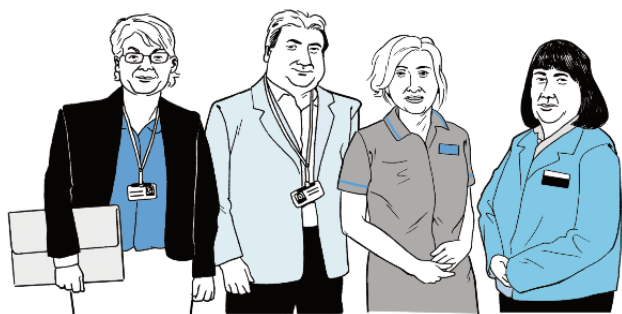
NHS England developed a plan to help people share their views. These people included individuals and groups who would be affected by the accessible information standard or would have to put the standard in place.



Examples of people and organisations included:

- NHS organisations including clinical commissioning groups (CCGs) and foundation trusts;
- Adult social care bodies (local authorities);





- Organisations providing NHS or adult social care services;
- Relevant royal colleges such as the Royal College of Nursing (RCN);
- Voluntary and community sector organisations working with and / or led by people with disabilities which affect their communication and information needs;



- Professionals and individual service users who had previously expressed interest in this work;

- Local Healthwatch and other patient groups.

Information about the project and details of ways to get involved were promoted through bulletins, newsletters, email, websites and social media.



# 4 Summary of survey activity



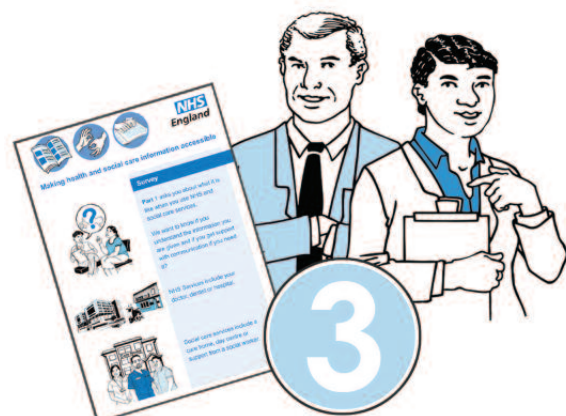
Three surveys were developed to seek views from different groups:

- A survey aimed at patients, service users and carers;



- A survey aimed at health and care professionals and organisations;

**healthwatch**



- A survey aimed at voluntary organisations, patient groups, local Healthwatch and communication professionals.





The three surveys were hosted online at:

[www.engage.england.nhs.uk](http://www.engage.england.nhs.uk)



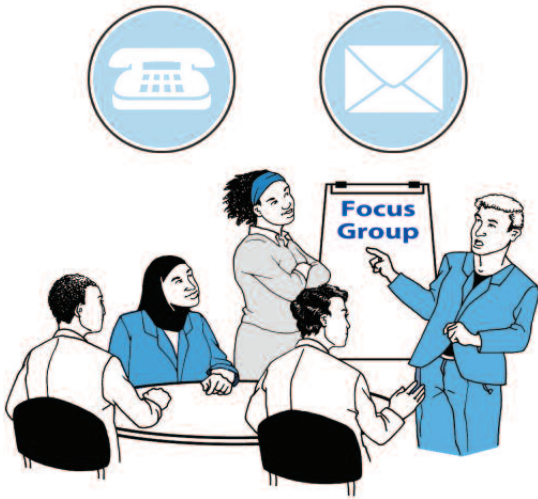
All three surveys were available in Word document format to help people using screen readers and to allow printing.



The patient, service user and carer survey was also available from the website in easy read format, as a British Sign Language (BSL) video with subtitles, and in audio format.

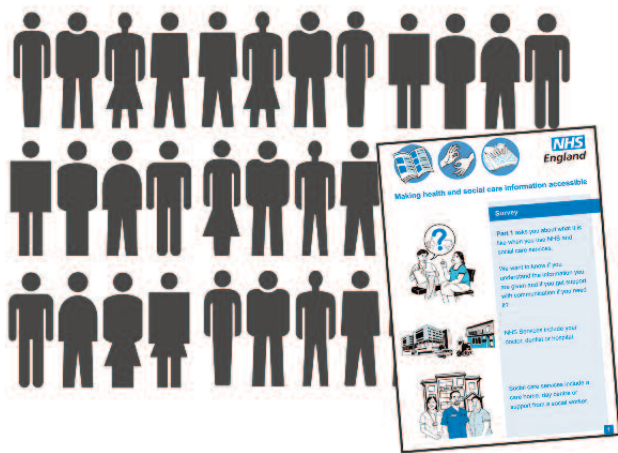


Paper copies of the survey in standard print, large print, braille, and easy read were also available on request.



If anyone had difficulty in reading or responding to the survey they could respond by mail, telephone or attend a workshop.

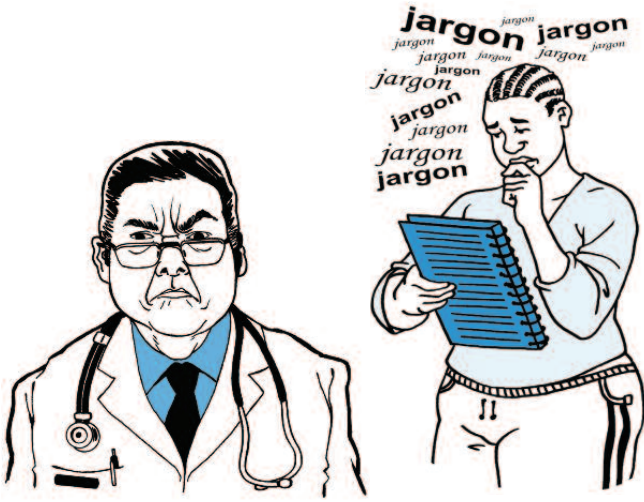
## Key findings from patient, carer and service user surveys



675 surveys were received from patients, carers and service users.

Most people did not get the support they needed to communicate when using NHS or social care services, but some did.





Most people did not receive information in a format they can use when using NHS or social care services, but some did.



Most people missed out on some important information about their care, but some did not.



People felt that if health and social care organisations always gave them information they could understand and communication support then they would have:

- More independence, and control over their lives;





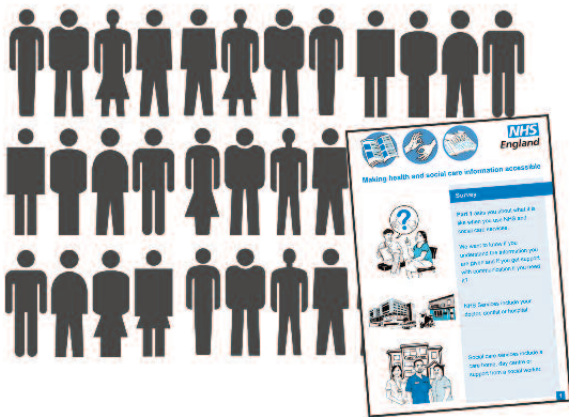
- More privacy and a right to confidentiality;
- They would be more confident and less stressed or anxious;
- And there would be improvements in patient safety, choice and access.

Most people wanted to be asked face-to-face about what support they needed to communicate.

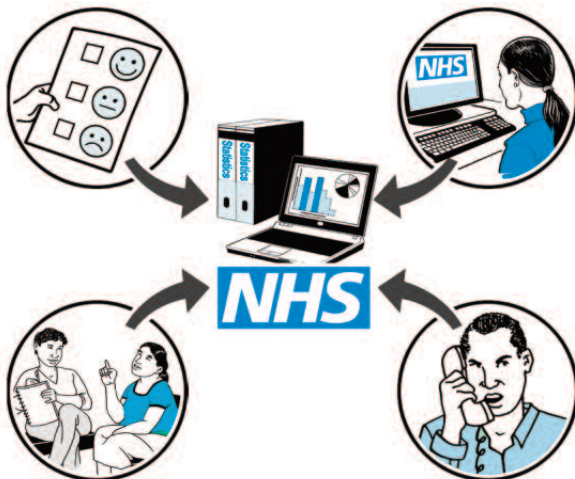


Other ways are email, letter, text, online form, telephone, easy read, BSL and social media.

## Key findings from health and care professionals and organisations survey



A total of 299 completed surveys were received from NHS and social care professionals.



Most organisations reported that they routinely record information, but some did not.



Most organisations reported that they record information in an electronic system, but some use paper records, care plans, or health passports.

Most people are asked about their needs as part of the initial assessment, but some are not.

Sometimes carer needs are asked but not all the time, and this is usually recorded in the patient record.

Sometimes the carer has their own record.

Most organisations would provide different formats within the organisation, but some would go to suppliers to provide this.



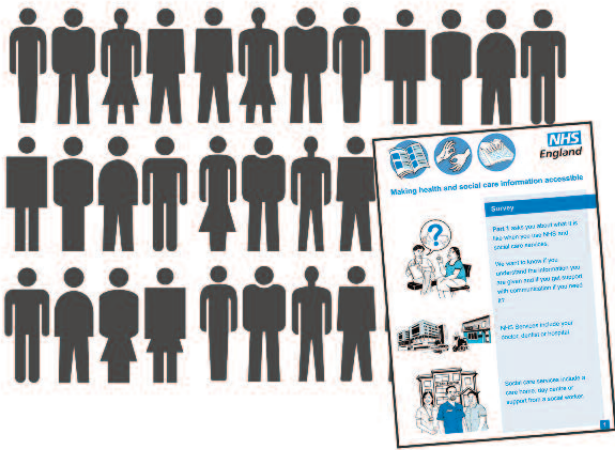


Some organisations had difficulty in recording or responding to support needs.



If people needed a different format or communication support they would have to wait longer. Sometimes hours, sometimes days.

# Key findings from support and supplier organisation survey



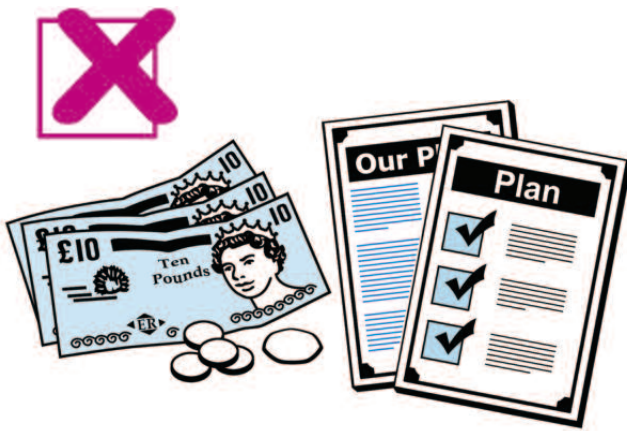
A total of 173 completed surveys were received.

Poor communication, use of difficult words (jargon and acronyms) made it difficult to provide different formats of information.

People said that there is a lack of BSL interpreters, or the interpreters are unqualified and not very good.



Some staff are inconsiderate, rude or impatient. It is suggested to provide deaf awareness and customer service training to staff.



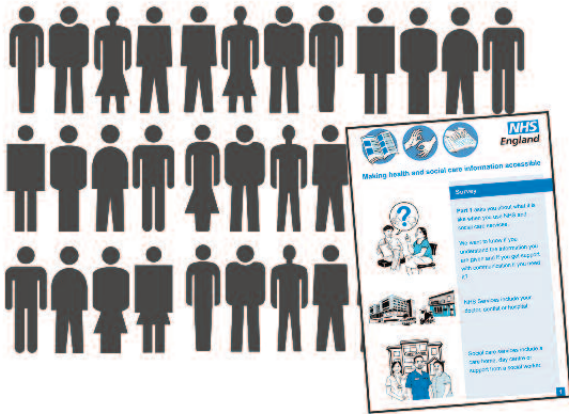
Some organisations do not have procedures, plans, money, or equipment to provide alternative formats.

## 5 Summary of workshops



SignHealth, RNIB, Action on Hearing Loss, CHANGE, Sense, Wandsworth Council Adult Social Services and Bradford Talking Media hosted workshops as well as some other groups.





Over 150 people had their say across the country.



People usually did not get the communication support they needed, and lots of people got letters that they cannot read.



Organisations should offer more ways for people to contact them, like telephone, text and email.



Details of needs should be recorded and shared with other services providing care and people shouldn't have to explain it over and over.



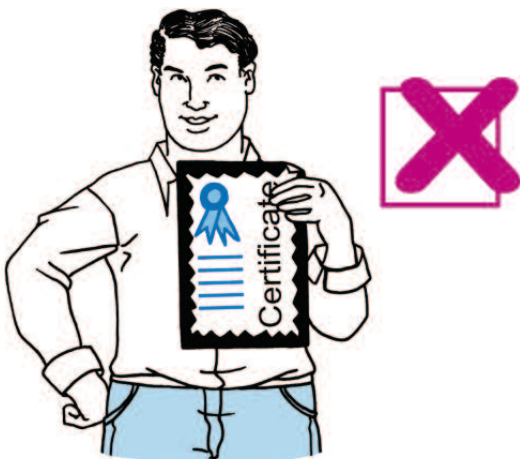
Services should provide correspondence and information in a range of accessible formats, like easy read, large print, email, braille, audio and BSL video.



People with sensory loss and/or a learning disability can access services independently and participate in decisions about their health and care with the right information and tools available.



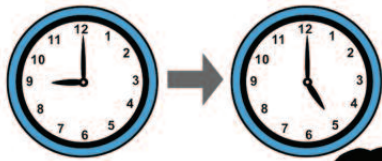
People who need a different format had long delays getting information. They could wait up to 14 days if an interpreter was needed for an appointment.



Some interpreters were not suitably qualified,



People were not able to request a male or female interpreter.



And interpreters are not always available out of hours.



People were not informed when an interpreter was booked.

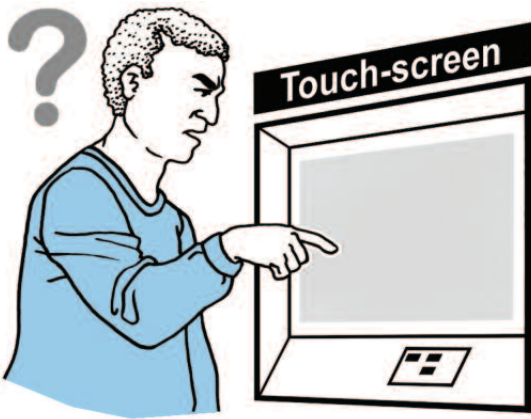


Some people felt they needed to fight to get a suitable format of information.





Waiting areas can be very frustrating places.



Many people struggled with 'scrolling screen' or other visual alerts or displays, and with touch-screen 'check in' systems, because they were unable to see or read them.



Many participants also struggled with verbal or audible alerts because they were unable to hear them and / or unsure where to go or what action to take based on the alert.



Some participants had waited for several hours in a waiting area unaware that their turn had been and gone, and / or waiting for an interpreter to arrive.



Some people shared positive experiences of simple steps taken by staff to overcome difficulties.



For example guiding the person to a seat outside the relevant consultation or treatment room or coming to 'collect' them when it was their turn.



Positive experiences were also shared of staff who had really helped people by taking the time to ensure that they had understood information.



Participants who used hearing aids expressed frustration that many health and social care premises did not have induction loops.



And of those that did, they often did not work or staff were unaware of how to use them.



People suggested that staff can make a significant impact to people's experience by:

- Allowing time for the patient to ask questions.
- Writing information down.
- Guiding them to a seat in the appropriate waiting area.







- And allowing longer appointment times.



People suggested that more information should be available in a range of accessible formats online.



This included information about common conditions, symptoms, services, healthy lifestyle advice, and complaints procedures.

# 6 Feedback received on the engagement process



Some voluntary sector organisations and individuals provided feedback on the engagement process.



Some people felt that the BSL video was not acceptable for deaf people with a learning disability.



Some people felt that the written survey was too complicated and difficult.



Some people felt that the easy read survey was too long, and had too many options.

We listened to this feedback and will do better next time.

## 7 Impact of engagement



We will use the information provided in surveys and workshops to write the accessible information standard and inform how organisations will put this in to practice.

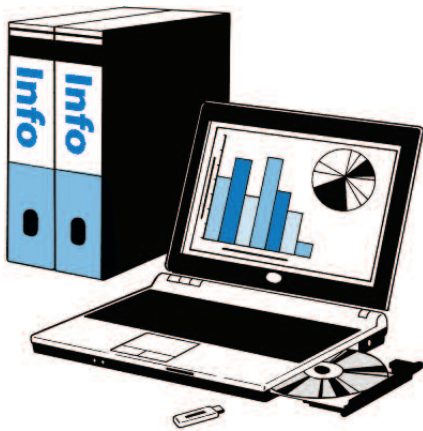




We will not be including a standard question to find out about people's needs in the standard.



We will tell organisations to think about how information is shared between care providers.



We will tell organisations to record information in a consistent way.



We will tell organisations to use appropriately trained interpreters.



We will be asking organisations to allow more time for appointments.

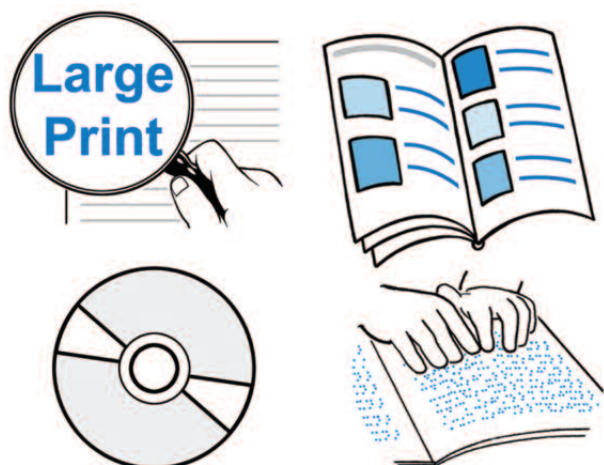
# 8

## Contacts and alternative formats



Copies of this report are available in, British Sign Language (BSL) video (with subtitles), and audio formats from the NHS England website:

[www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)



The report can also be posted out as a hard copy, in large print, easy read, on CD, on DVD or in braille on request.



If you wish to request a copy of the report, or if you have a query or concern about its contents, please email:

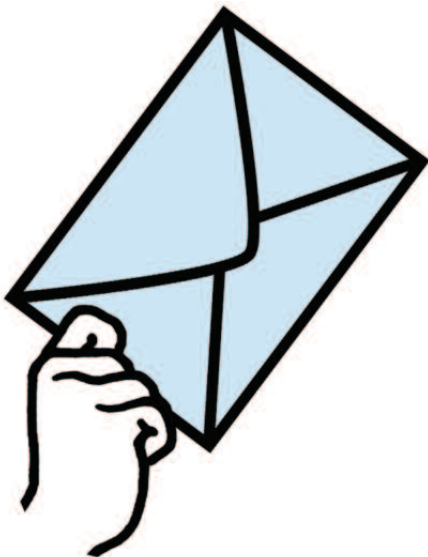
**[england.nhs.participation@nhs.net](mailto:england.nhs.participation@nhs.net)**



Alternatively, you can telephone us on:

**0113 8251324**

or write to:



**Sarah Marsay, Public Voice Team (Accessible Information), NHS England, 7E56, Quarry House, Quarry Hill, Leeds, LS2 7UE**



Easy

Read

## **NHS England** Engagement Activity Report

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social care information  
accessible

November 2013 - February 2014

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This easy read document was produced by CHANGE  
[www.changepeople.org](http://www.changepeople.org)

