

What adults with learning disabilities say about health research



A summary report of REN2 consultation workshops carried out during January - March 2024

Research Engagement Team (REN), Research and Innovation, Norfolk and Waveney Integrated Care System (ICS)

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The views expressed in this publication are those of the author(s) and not necessarily those of NHS England or the Department of Health and Social Care.



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Why this matters so much

Health inequalities and people with learning disabilities *1

	<p>People with learning disabilities die younger.</p> <p>On average women die 23 years younger, men die 20 years younger than people without learning disabilities in the general population (LeDeR, 2023*2)</p>
	<p>People with learning disabilities are at risk of diagnostic overshadowing where medical staff assume how someone is behaving is because of their learning disability, They do not check properly for things like pain, illness, infection.</p>
	<p>Any group 'left out' of health research is at risk of unintended side effects of treatments. Frequently the groups who are excluded are those who have the poorest health outcomes.</p>

*1 https://www.ndti.org.uk/assets/files/IHaL_2011_healthinequalities_socialcare_guidance_final.pdf

*2 <https://improvinglivesnw.org.uk/our-work/healthier-communities/mental-health/learning-disabilities-and-autism/>



Key messages to remember in future

People may need support to make the arrangements to take part



Planning and arranging transport, having a packed lunch to bring, managing your support timetable - all these are tricky

No-one is talking to people with learning disabilities about research



People will not know about health research they could take part in unless they are told about it (in an accessible way)

Remember about being fair and equal



If you design something online you have to be honest about how this stops a lot of people taking part.

The 'whole world' is not actually online yet!

Do no harm – coproduce your research so this works at every level



A topic which does not seem scary can be really difficult for some groups, work *with* experts by experience as much as possible

What we did



We bid for some money so we could run workshops about health research for people with learning disabilities.



Two Opening Doors Advisers had 'Research Ready' training from Ren2 Workers.



A planning group made up of people with learning disabilities worked with two Advisers to understand the project questions.



Some of our sessional workers and our Senior Adviser did training about how to put the results into the computer at the end.



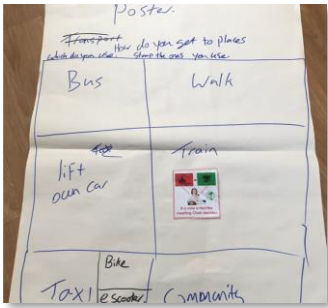
From the training workers said they needed to know what each individual person said.

The planning group decided to give each person a 'stamp' so we knew which ones were their answer sheets.



The planning group designed an accessible workshop to give people with learning disabilities a space to share their views about health research.

***please contact us to talk about making your research materials accessible ↓**



The Planning group tried out lots of different resources for people to give their views.



An easy read worker coproduced the workshop resources – working with an Opening Doors expert by lived experience.



We tested out our ideas with a self advocate who said what bits they could understand and what was too hard.



We visited groups across Norfolk and ran the workshops there. Each workshop was led by a person with a learning disability.



Each expert by experience trainer was paid for their time at the Real Living Wage.



Having peer trainers lead the workshops was very important so that people with learning disabilities felt safe to have their say.



We made certificates for each person who took part in a workshop.

It is important to value peoples' time and effort.



We told each group we would come back with an accessible presentation so they could see the results of the consultation.

These sessions would be led by peer trainers.



In total **44 people with learning disabilities** took part in the consultation workshops.

Cromer	Norwich	
8 people	16 people	
Diss	Great Yarmouth	People from secure services
3 people	11 people	6 people

These colours are used as a key throughout this report



Once we had finished the workshops all the papers went to our sessional workers. They put them into the Integrated Care Board 'Community Voices' computer system.



We began adding up all the answers so that we could do the report to show groups the result of their work.



Our Advisers helped us think how to put the report together. We coproduced it ready to go back to the ICB so they can see the result.



We made a presentation to take to the groups about the health research work. We made sure it is simple. People could also have a copy of this report as well if they want to.

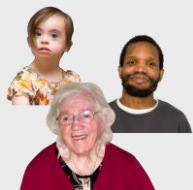


All the way through the project we talked with one of the ICB Officers as we knew we were doing things differently from the others. We wanted to check the ICB would be happy with the way we were running things and they would get the data they needed.



About the people we spoke to

Age range – not everyone told us their age



18-24	25-34	35-44	45-54	55-64	65+
5	8	6	15	8	1

18-24	1	0	0	2	2	25-34	1	2	0	5	0
35-44	1	2	1	2	0	45-54	4	6	1	1	3
55-64	1	5	1	1	0	65 +	0	1	0	0	0

Gender – not everyone told us their gender



Male	Female	Transgender
23	21	0

Male	4	7	5	8	3	Female	4	7	5	8	3
------	---	---	---	---	---	--------	---	---	---	---	---

Number of health conditions

18-24	5	0	0	7	3	25-34	0	6	0	12	0
35-44	5	14	5	4	0	45-54	13	20	5	3	22
55-64	5	19	7	5	0	65 +	0	7	0	0	0

Number of people with no health condition

0	1	0	0	0
---	---	---	---	---

KEY **Cromer** **Norwich** **Diss** **Great Yarmouth** **Secure Services**



About the people we spoke to

About people's health conditions

<p>Poor mental health </p> <p>36</p> <p>7 12 3 8 6</p>	<p>Mobility issues </p> <p>9</p> <p>1 5 0 2 1</p>	<p>Breathing issues </p> <p>13</p> <p>3 6 2 0 2</p>	<p>Allergies </p> <p>14</p> <p>4 5 0 3 2</p>
<p>Back pain </p> <p>15</p> <p>3 8 0 2 2</p>	<p>Hearing issues </p> <p>7</p> <p>1 4 2 0 0</p>	<p>Cancer </p> <p>1</p> <p>0 0 1 0 0</p>	<p>Skin problems </p> <p>11</p> <p>4 4 0 2 1</p>
<p>High or low blood pressure </p> <p>13</p> <p>2 9 0 1 1</p>	<p>Heart problems </p> <p>4</p> <p>0 1 1 0 2</p>	<p>Diabetes </p> <p>9</p> <p>1 4 2 1 1</p>	<p>Weight issues </p> <p>15</p> <p>2 4 2 5 2</p>
<p>Addiction(s) </p> <p>7</p> <p>0 1 1 1 4</p>	<p>Eye Problems </p> <p>3</p> <p>2 1 0 0 0</p>	<p>I have no health conditions </p> <p>2</p> <p>0 1 0 0 1</p>	<p>This is the total number of people with each condition</p>

KEY **Cromer** **Norwich** **Diss** **Great Yarmouth** **Secure Services**



About the people we spoke to

Where people live – and where they travelled to take part

Where people live	No. of people	Miles to event
Sheringham	2	8
Cromer	6	1-3
Shelfhanger	1	4
Harleston	2	10
Secure Services setting	5	0
Gorleston, Bradwell	2	3-6
Great Yarmouth	3	1-3
Kings Lynn	1	45
NR5 - Costessey, Bowthorpe	3	5
NR7 - Sprowston, Thorpe St Andrew	5	3
NR10 – Reepham, Spixworth, Buxton	1	9
NR3 – Hellesdon, North Norwich area	3	1
NR9 – Hethersett, Hingham area	1	10
NR13 – Reedham, Acle, Rackhealth	1	12
NR1 – Lakenham, Thorpe Hamlet	1	2
No postcode given	6	Cannot tell











People in rural areas where there is worse transport often have the longest way to travel to take part

People with 0 miles lived in secure service settings ... if you do not travel to them they cannot take part



About the people we spoke to

How people get to places Total number who said this

<p>Bus</p>  <p>33</p> <p>7 14 2 7 3</p>	<p>Walk or wheel</p>  <p>34</p> <p>8 12 3 8 3</p>	<p>Own car or get a lift</p>  <p>28</p> <p>3 11 3 9 2</p>	<p>Train</p>  <p>21</p> <p>4 7 3 4 3</p>
<p>Taxi</p>  <p>23</p> <p>6 10 1 3 3</p>	<p>Bike</p>  <p>1</p> <p>0 1 0 0 0</p>	<p>E-scooter</p>  <p>1</p> <p>0 0 0 1 0</p>	<p>Community transport</p>  <p>4</p> <p>1 0 0 2 1</p>

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Some people cannot use public transport – there can be different reasons for this (anxiety, being able to travel alone safely, not being taught are some examples)

Most people said walking/wheeling so they are more likely to go to places nearby



If people have to get a taxi to take part this may put them off as it is expensive and can be hard to book

For public transport people need clear directions and a good route to take part



What we found out

Where people would go to take part in research

Total number who gave each answer

<p>GP – Doctors Surgery</p>  <p>36</p> <p>7 12 3 8 6</p>	<p>Hospital</p>  <p>24</p> <p>4 9 2 4 5</p>	<p>Local Pub</p>  <p>16</p> <p>0 7 2 5 2</p>	<p>Village Hall</p>  <p>15</p> <p>6 2 3 2 2</p>
<p>School</p>  <p>11</p> <p>3 3 0 2 3</p>	<p>Community Centre</p>  <p>23</p> <p>6 7 3 3 4</p>	<p>Pharmacy</p>  <p>25</p> <p>6 9 0 6 4</p>	<p>Shopping Centre</p>  <p>27</p> <p>2 11 2 6 6</p>
<p>Day Centre Hub</p>  <p>17</p> <p>3 3 1 9 1</p>	<p>Learning Disability Social Club</p>  <p>22</p> <p>5 6 2 7 2</p>	<p>Residential Home</p>  <p>13</p> <p>3 3 3 2 2</p>	<p>Secure Services</p>  <p>10</p> <p>4 2 0 1 3</p>
<p>Library</p>  <p>29</p> <p>6 7 3 9 4</p>	<p>Charity Shops</p>  <p>23</p> <p>3 9 2 5 4</p>	<p>Leisure Centre</p>  <p>22</p> <p>4 9 1 6 2</p>	<p>Number of people who did not do this question</p> <p>2</p> <p>0 1 1 0 0</p>

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What we found out

Where people would go to take part in research

Other ideas on where people would go to take part in research with the number of people who gave that suggestion

Holt Country Park	1	PHAB Club* ¹	1	Church	2
Self Advocacy Organisation	1	British Sign Language	1	Costa/Greggs	1
Public Transport	1	Salvation Army	1	Senior Citizens Club	1
Garden Centre	1	Park	1	Waterloo Park Café	1
Private Pool	1	* ¹ https://www.phab.org.uk/clubs/			

Lots of people have different ideas about where they would feel comfortable taking part in research

People felt they would like to have choice about where to take part and be involved



Some of the places are not "traditional" settings for research the thing is to think outside the box




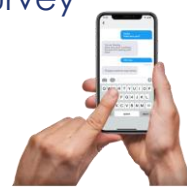

For many people the place needed to be somewhere they know already



What we found out

How people would like to have their say about health research

Total number who gave each answer

<p>Interactive workshop</p>  <p>26</p> <p>3 13 3 4 3</p>	<p>Easy read questionnaire</p>  <p>27</p> <p>5 12 3 5 2</p>	<p>In a group</p>  <p>30</p> <p>6 14 3 4 3</p>	<p>1:1 interview</p>  <p>27</p> <p>5 12 2 5 3</p>
<p>Online survey</p>  <p>14</p> <p>2 7 0 4 1</p>	<p>Online meeting</p>  <p>16</p> <p>3 6 2 3 2</p>	<p>Text survey</p>  <p>10</p> <p>2 5 0 2 1</p>	<p>Phone call</p>  <p>9</p> <p>0 0 0 6 3</p>
<p>KEY Cromer Norwich Diss Great Yarmouth Secure Services</p>			

Comments – with the number of people who said this

Need support to fill all these in	1	Speak on phone	1
Phone call could be scam	1	Getting together as one group	1
Questionnaire by post	1	Letter	2
Need to ask for help with these	1	Face to face on paper	2
I need to know the person	2		

“I am feeling a bit overwhelmed with this many questions”

“I don't feel comfortable with too many questions makes me feel stressed out. I am not very good with new people”

“It takes me time to come up with an answer – I need lots of time and some questions can confuse me”



What we found out

How people would like to have their say about health research

“There was too many questions and I felt overwhelmed”

“Being asked questions in a place I am familiar with is ok but in a situation where I don't know I get stressed”

“I like my group and I like doing things in the morning and the afternoon but this felt a lot to do”

“If there are too many pictures and words then it is muddling and confusing. If a page had 2 to 3 pictures with easy words that is better”

“Venues need to be quiet and less people around because of my anxiety. The Library is quiet. I cannot queue to get into places”

People have the right to **reasonable adjustments** that they need to be able to take part – this may be information that is accessible to them, the chance to work with someone they know there to support or extra time and/or extra sessions



Some people can take part better at certain times of day because of side effects of medication they take

Ask people what they need to be able to take part and feel safe



What we found out

Reasons people **would** take part in research

Total number who gave each answer

<p>Easy Read information</p>  <p>32</p> <p>6 14 3 5 4</p>	<p>Easy read report</p>  <p>31</p> <p>7 14 3 3 4</p>	<p>Research interests me</p>  <p>34</p> <p>5 15 3 7 4</p>
<p>Helping other people</p>  <p>35</p> <p>6 15 3 7 4</p>	<p>Being given something</p>  <p>26</p> <p>4 12 3 3 4</p>	<p>The research is online</p>  <p>13</p> <p>2 7 0 3 1</p>
<p>My views will be heard</p>  <p>30</p> <p>7 14 3 3 3</p>	<p>Helps me learn about health</p>  <p>34</p> <p>7 14 3 7 3</p>	<p>To meet new people and see friends</p>  <p>34</p> <p>7 15 3 6 3</p>

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Comments – other things people said

- I need pictures, if it is all words then I'm gone
- It is important to hear peoples views
- Things need to be interactive



What we found out

How people feel about research that is done **in person**

Total number who gave each answer

Reasons people **would** take part

<p>We meet face to face</p>  <p>35</p> <p>7 15 3 6 4</p>	<p>The venue is easy to get to</p>  <p>35</p> <p>7 15 2 7 4</p>	<p>The workshops have breaks</p>  <p>35</p> <p>6 15 3 7 4</p>
<p>The venue is accessible</p>  <p>30</p> <p>6 14 3 3 4</p>	<p>I can bring along a trusted supporter</p>  <p>34</p> <p>7 14 3 6 4</p>	

Reasons people **would not** take part

<p>Access needs to be better</p>  <p>13</p> <p>4 2 1 2 4</p>	<p>No money to get to places</p>  <p>18</p> <p>5 5 2 2 4</p>	<p>Do not like going out</p>  <p>11</p> <p>5 3 0 0 3</p>
<p>Travel is hard for me</p>   <p>16</p> <p>4 7 0 2 3</p>		

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What we found out

What would stop people taking part in research generally

Total number who gave each answer

<p>No support</p>  <p>36</p> <p>7 12 3 8 6</p>	<p>Busy in the day</p>  <p>24</p> <p>4 9 2 4 5</p>	<p>Lack confidence</p>  <p>16</p> <p>0 7 2 5 2</p>
<p>Do not want to share information</p>  <p>15</p> <p>6 2 3 2 2</p>	<p>Other people do not want me to</p>  <p>11</p> <p>3 3 0 2 3</p>	<p>Find it hard to trust who else is there</p>  <p>23</p> <p>6 7 3 3 4</p>
<p>Cultural or religious reasons</p>  <p>25</p> <p>6 9 0 6 4</p>	<p>Do not want to be upset</p>  <p>27</p> <p>2 11 2 6 6</p>	<p>Do not understand</p>  <p>17</p> <p>3 3 1 9 1</p>

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People often need to be given the chance to take part in research by someone they trust







Researchers need to work with organisations who **see** people with learning disabilities regularly



What we found out

What would stop people taking part in **online research**

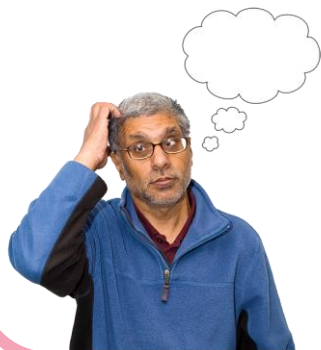
Total number who gave each answer

<p>Do not want to use a computer</p>  <p>17</p> <table border="1"> <tr> <td>2</td> <td>7</td> <td>0</td> <td>5</td> <td>3</td> </tr> </table>	2	7	0	5	3	<p>Can not afford equipment to go online</p>  <p>15</p> <table border="1"> <tr> <td>4</td> <td>3</td> <td>0</td> <td>4</td> <td>4</td> </tr> </table>	4	3	0	4	4	<p>Do not know how to use a computer</p>  <p>8</p> <table border="1"> <tr> <td>1</td> <td>1</td> <td>0</td> <td>3</td> <td>3</td> </tr> </table>	1	1	0	3	3
2	7	0	5	3													
4	3	0	4	4													
1	1	0	3	3													
<p>Not allowed to use a computer</p>  <p>7</p> <table border="1"> <tr> <td>2</td> <td>0</td> <td>1</td> <td>1</td> <td>3</td> </tr> </table>	2	0	1	1	3	<p>Happy to take part in online research</p>  <p>13</p> <table border="1"> <tr> <td>4</td> <td>2</td> <td>0</td> <td>3</td> <td>4</td> </tr> </table>	4	2	0	3	4	<p>Did not answer the question</p>  <p>5</p> <table border="1"> <tr> <td>1</td> <td>1</td> <td>0</td> <td>1</td> <td>2</td> </tr> </table>	1	1	0	1	2
2	0	1	1	3													
4	2	0	3	4													
1	1	0	1	2													

KEY Cromer Norwich Diss Great Yarmouth Secure Services

Online research suits some but it can add to people with learning disabilities being left out

Researchers sometimes do easy read outlines of a research project but then direct people with learning disabilities to online questionnaires that they cannot understand



Digital exclusion is a big issue for people with learning disabilities. 15% of this population have never been online and 35% lack basic digital skills to navigate online resources (Good Things Foundation, 2022).



What we found out

A summary of what matters to people with learning disabilities about health

these are displayed by area on the following pages →



Healthy living including healthy foods, healthy drinks and exercise

Diabetes



Health checks and regular check-ups

GP / doctors issues – getting appointments and seeing the same person



Mental health including anxiety + wellbeing

Reasonable adjustments



What we found out

What is important to people with learning disabilities about health

Cromer self advocates' views

Healthy eating
Healthy Foods
Heathy drinks

Taking medication

Exercise

Hobbies

**Seeing the
doctor regularly**

**Looking after
my feet**



What we found out

What is important to people with learning disabilities about health

Norwich self advocates' views





What we found out

What is important to people with learning disabilities about health

Diss self advocates' views

Healthy Food

Fresh air

Being independent

I want health checks

Seeing GP regularly

Medication

Stress and anxiety

It is expensive to go to the hospital - £12.50 to get home as no hospital transport



What we found out

What is important to people with learning disabilities about health

Great Yarmouth self advocates' views

Healthy lifestyle

Seeing the same doctor with support

Reducing sugar

Seeing the physio for leg problems

Mental health help quickly

Keeping fit and exercise

Taking my meds

Diabetes

Wearing my special boots as I cannot walk without them

Seeing my doctor

Healthy eating

Understanding Slimming World



What we found out

What is important to people with learning disabilities about health

Secure Services self advocates' views

Being independent

Keeping fit and exercise

Eat healthy

Lose weight

Heart Conditions

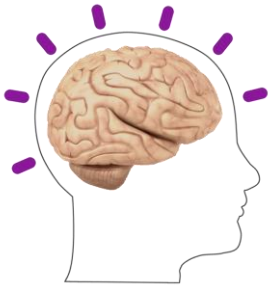
Do more exercise



What we found out

A summary of what health research people want to have their say about

these are displayed by area on the following pages →



Specific conditions like hydrocephalus, epilepsy, asthma



Diabetes



Mental health issues



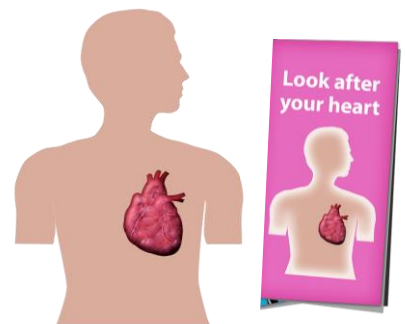
Ways to improve health like stopping smoking, exercise and losing weight



Bloods tests and blood pressure



Sexual health and parenting



Heart conditions



What we found out

What health research did people want to have their say about

Cromer self advocates' views

Diabetes

Stopping infections

Schizophrenia

Asthma

Water on the brain

How scientist stop illnesses by inventing cures

Anaemia

Clearer food labels to choose healthy foods and drinks

Epilepsy

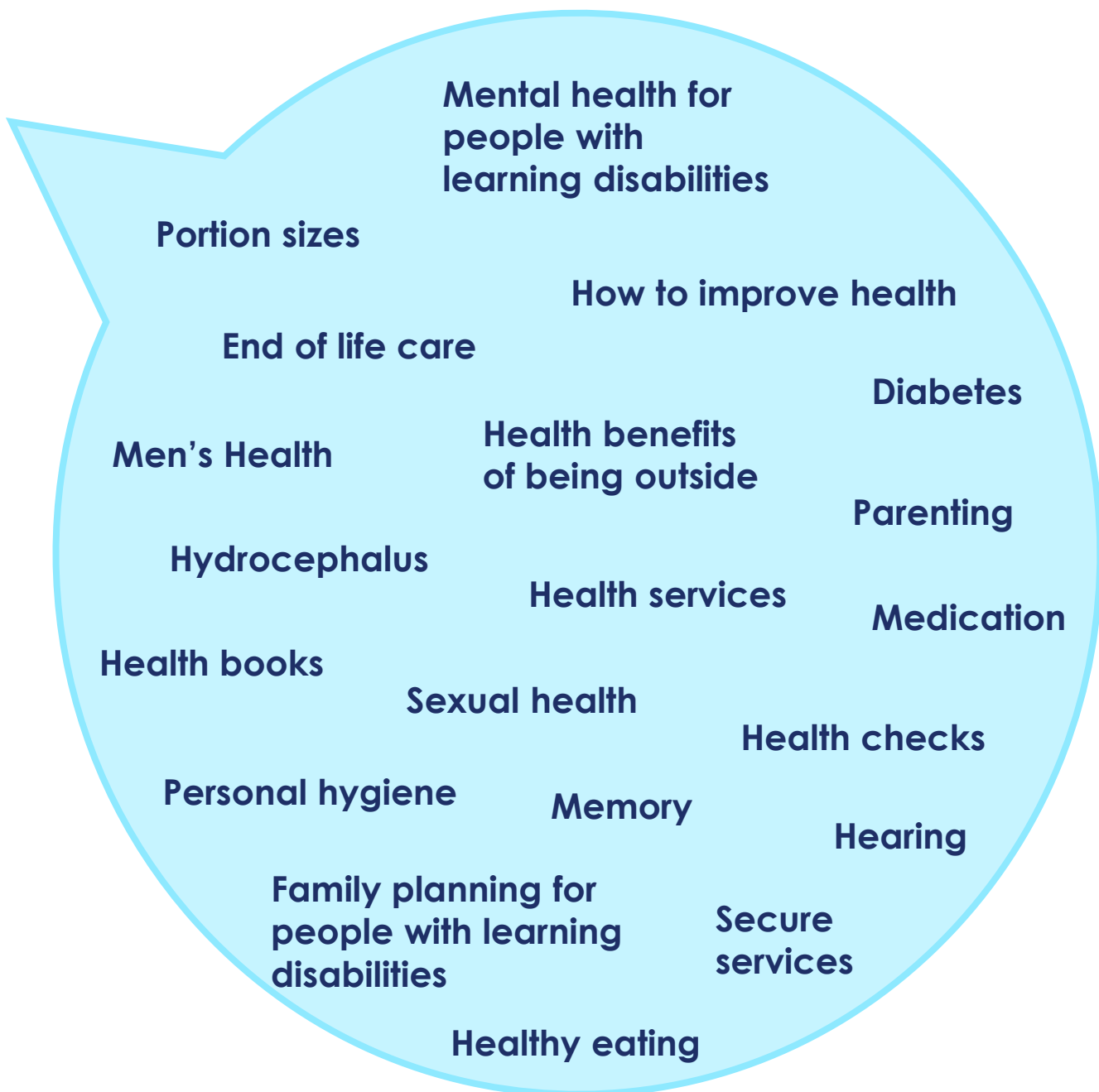
Lymphoedema



What we found out

What health research did people want to have their say about

Norwich self advocates' views





What we found out

What health research did people want to have their say about

Diss self advocates' views

Weight programmes

Blood tests

Mental health

Diabetes

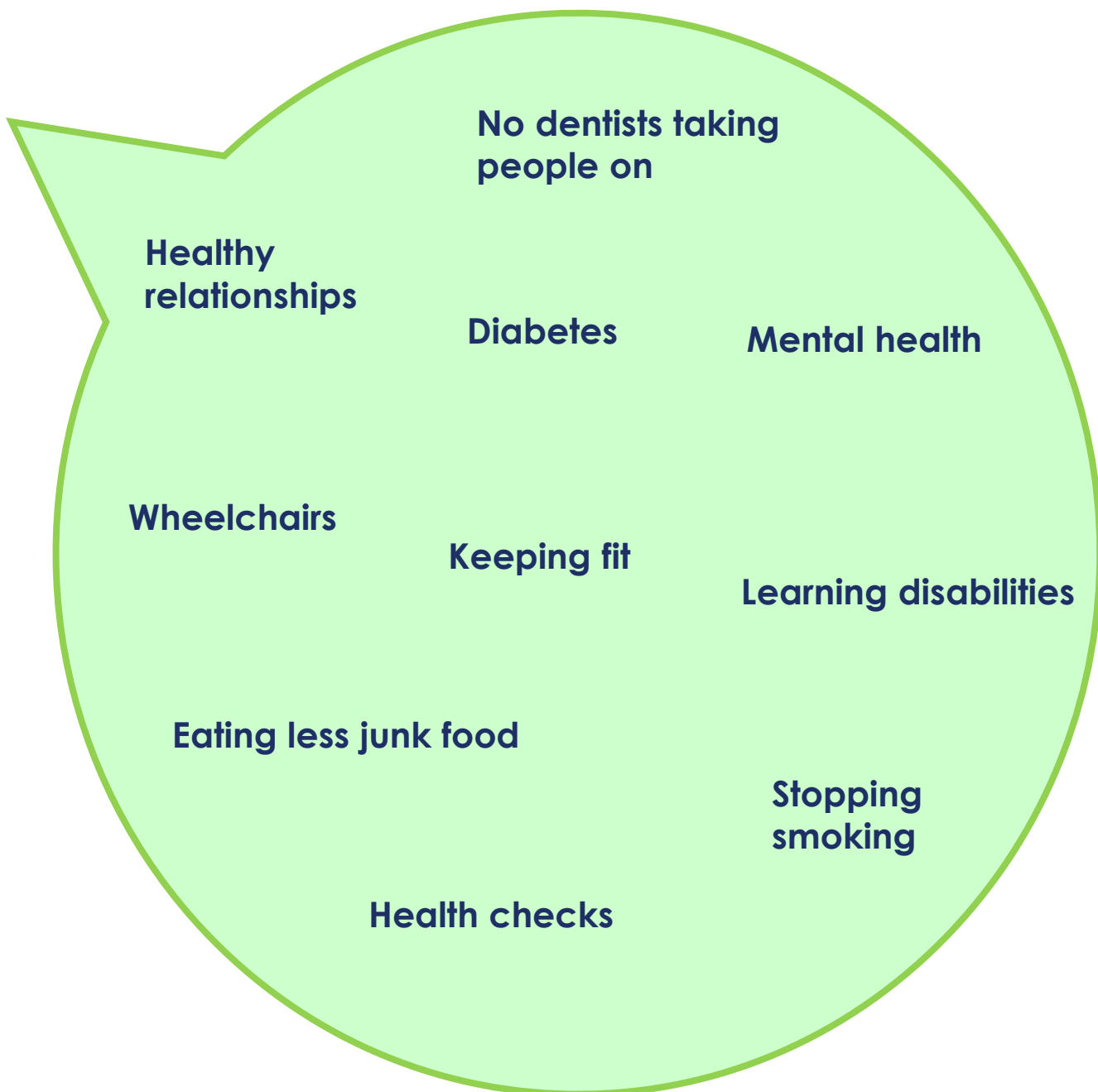
Heart disease



What we found out

What health research did people want to have their say about

Great Yarmouth self advocates' views





What we found out

What health research did people want to have their say about

Secure services self advocates' views

Diabetes

Mental health

Heart conditions

Blood pressure



Appendix 1

The accessible Presentation we used

Your say about health research

Improving lives together
Norfolk and Weymouth Integrated Care System

Our Research

Research is when you do work to find out about things

Today is about health research

www.openingdoors.org.uk © Opening Doors Training Group 2024

Photographs

We will be taking photos during our workshop for us:

- in our easy read report
- on social media
- on our website

www.openingdoors.org.uk © Opening Doors Training Group 2024

What today is about

This session is about health research and what health issues are important to you.

You will be taking part in a workshop - you can draw, write and stick things on to have your say.

www.openingdoors.org.uk © Opening Doors Training Group 2024

What we are going to do

We will have a break half way through.

We are here to talk if these questions bring up any difficult feelings or bad memories.

www.openingdoors.org.uk © Opening Doors Training Group 2024

Let's get started – all about you

Please choose a stamp to use for you
You can keep this

Please fill in the **About Me** sheet

Stamp it with your stamp

Look through the health conditions and tell us which ones you have
you can leave this blank if you want

www.openingdoors.org.uk © Opening Doors Training Group 2024

How to take part

Every table has a different question sheet on

Go round and do as many as you want to

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Example Tell us how you get about

Getting around – stamp the ones you use

Bus	Walk or wheel	Lift in my wheelchair	Train
Taxi	Bike	E-scooter	Community transport

Put a stamp next to each one that you use

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Any questions? Let's get started


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Appendix 2


Accessible personal information, consent and health conditions form

About me
My health conditions

 You can fill this form in with a supporter.


 Put your stamp in the pink box.

My stamp




Fill in the orange boxes below. Leave them blank if you do not want to say.

Write your age **Write the first part of your postcode**

 **NR3**







I am... (please mark 1)

Female Male Transgender

 Please turn over and tell us about your health conditions →

My health issues

Use your stamp to tell us the health conditions you have

 I have... High or low blood pressure	 I have... Heart problems
 I have... Diabetes	 I have... Weight issues
 I have... Addiction problems Smoking / Alcohol / Drugs	 I have... Eye problems

 I have... Mental health problems	 I have... Mobility problems
 I have... Breathing problems Asthma, COPD	 I have... Allergies
 I have... Back pain	 I have... Hearing problems
 I have... Cancer	 I have... Skin problems

What happens next?

 **Improving lives together**
Havik and the Integrated Care System

Opening Doors staff will type your answers onto a computer for the Integrated Care Board (ICB). We will put what you signed on your name.

 The ICB will use this information to help them plan and deliver health services and health research.

 We will also save your answers on our computer system at Opening Doors. We will shred the paper copies.

I am happy to take part in this consultation.

 Please put the date

 Please sign here

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Appendix 3

The accessible workshop materials

Getting around – stamp the ones you use

 <p>Bus</p>	 <p>Walk or wheel</p>	 <p>Get a lift or in my own car</p>	 <p>Train</p>
 <p>Taxi</p>	 <p>Bike</p>	 <p>E-scooter</p>	 <p>Community transport</p>

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Stamp the places I would go to, to take part in research

<p>GP / Doctors surgery</p>  <p>GP Surgery</p>	<p>Hospital</p>  <p>NHS</p>	<p>Local Pub</p> 	<p>Village Hall</p>  <p>Village Hall</p>
<p>Day Centre Hub</p>  <p>Day Centre</p>	<p>Learning Disability Social Club</p>  <p>Social Club</p>	<p>Residential Home</p> 	<p>Secure services</p>  <p>Secure Hospital</p>
<p>School</p> 	<p>Community Centre</p>  <p>Community Life</p>	<p>Pharmacy</p>  <p>Pharmacy</p>	<p>Shopping centre</p>  <p>Shopping Centre</p>
<p>Library</p>  <p>Library</p>	<p>Charity Shops</p>  <p>Charity shop</p>	<p>Leisure centre</p>  <p>Leisure Centre</p>	<p>Other idea</p> 

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Appendix 3

The accessible workshop materials






How I would like to have my say about research

<p>Interactive workshop</p>  <p>workshop</p>	<p>Easy read Paper questionnaire</p> 	<p>Talking in a Group and being asked questions</p> 	<p>Meeting face to face to do a questionnaire</p> 	<p>Other ideas</p> 
<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>

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How I would like to have my say about research

<p>Online survey (I know how to do this)</p> 	<p>Zoom meeting or Teams call on the computer</p> 	<p>Text survey</p> 	<p>Phone-call survey</p> 	<p>Other ideas</p> 
<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>	<p>Your stamp if you agree</p>

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Appendix 3

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What health research would you like to have your say about



Fill in a speech bubble



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Tell us what is important to you about your health



Fill in a think bubble



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Appendix 3

The accessible workshop materials

Reasons why I would **not** want to take part in research

<p>I do not have the support to take part</p> <p>Your stamp if you agree</p>	<p>I am busy during the day</p> <p>Your stamp if you agree</p>	<p>I do not feel confident to take part</p> <p>Your stamp if you agree</p>	<p>I do not want to share information</p> <p>Your stamp if you agree</p>	<p>Other people do not want me to take part</p> <p>Your stamp if you agree</p>
--	--	--	--	--

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Reasons why I would **not** want to take part in research

<p>I do not trust who else will know what I have said</p> <p>Your stamp if you agree</p>	<p>I cannot take part due to cultural or religious reasons</p> <p>Your stamp if you agree</p>	<p>It makes me feel upset - memories</p> <p>Your stamp if you agree</p>	<p>I do not understand about research</p> <p>Your stamp if you agree</p>	<p>I would be happy to take part in research</p> <p>Your stamp if you agree</p>
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Reasons why I would **not** want to take part in research in person

<p>Access needs to be better</p> <p>Your stamp if you agree</p>	<p>Travel is hard for me to get to places</p> <p>Your stamp if you agree</p>	<p>I do not like going out</p> <p>Your stamp if you agree</p>	<p>I do not have the time to get to places</p> <p>Your stamp if you agree</p>	<p>I would be happy to take part in research in person</p> <p>Your stamp if you agree</p>
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Reasons why I would **not** want to take part in research online

<p>I do not want to use the computer or the internet</p> <p>Your stamp if you agree</p>	<p>I cannot afford the equipment to go online</p> <p>Your stamp if you agree</p>	<p>I do not know how to use a computer</p> <p>Your stamp if you agree</p>	<p>I am not allowed to use a computer</p> <p>Your stamp if you agree</p>	<p>I would be happy to take part in research online</p> <p>Your stamp if you agree</p>
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Appendix 3

The accessible workshop materials

Reasons why I would want to take part in research

<p>Have easy information so I understand how to take part</p>	<p>Easy read report at the end of the research shows my views</p>	<p>The topic of the research interests me</p>	<p>If what I say will help other people</p>	<p>I am given something for taking part</p>
Your stamp if you agree	Your stamp if you agree	Your stamp if you agree	Your stamp if you agree	Your stamp if you agree

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Reasons why I would want to take part in research

<p>The research is online. I have the equipment and know how to use it</p>	<p>I will get my views heard and have my say</p>	<p>The research helps me learn about different things to do with health</p>	<p>I want to go to meet new people and see my friends</p>	<p>Write in any other ideas</p>
Your stamp if you agree	Your stamp if you agree	Your stamp if you agree	Your stamp if you agree	

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Reasons why I would want to take part in research in person

<p>We meet up face to face</p>	<p>The venue to do the research is easy to get to</p>	<p>The workshops have breaks in them</p>	<p>The venue is accessible and has good accessible toilets</p>	<p>I can bring someone to support me</p>
Your stamp if you agree	Your stamp if you agree	Your stamp if you agree	Your stamp if you agree	Your stamp if you agree

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Report written by Opening Doors

with support from



Please get in touch for information, advocacy support or to discuss advice on making your research design and materials accessible



**Our phone number is answered
Monday to Friday 9am to 5pm**



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