



Doctors and Us



What it is like for people with learning disabilities to go to the doctor in Ireland



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Contents

Photo	Section	Page
	Key Points	6
	Authors	9
	Thank you notes	12
	Words We Use	13
	Chapter 1: Opening	18
	Chapter 2: What steps did the IRN take to do this project?	20
	Chapter 3: Who did we talk to?	26
	Chapter 4: What we Learned	29
	Feeling Looked After	31
	Taking Charge of My Health	34



Making Doctors' Visits Better

39

Chapter 5: Links to Other research

43

Chapter 6: Key Messages

48

Chapter 7: IRN Thinking Back on the Project

55

Chapter 8: Books and Papers Used in this Report

62

Key Points

The IRN



The IRN is a group who does research that is important to people with learning disabilities in Ireland.

Doctors and Us Project



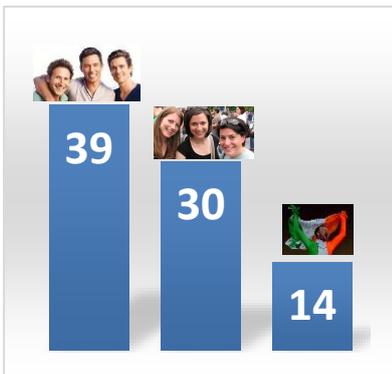
This book is about a research project we did to learn what it is like when people with learning disabilities in Ireland visit their doctor.

How did we find out about people's stories?



IRN looked for people who wanted to talk in focus groups about doctors' visits.

The people we talked to



- We did 12 focus groups with a total of 69 people with learning disabilities from Ireland
 - 39 men and 30 women
- They were, on average, 45 years of age
- 14 supporters also took part. They agreed only to talk when asked to do so.

Finding connections



We wrote word by word what people told us. We worked together to:

- Write key points from each focus group
- See how the stories linked up and where they were different.

What we found out

There were 3 key findings



People **felt looked after** when the doctor's office was:

- easy to access
- people felt welcome and
- people felt at ease

People **felt in charge** of their health when:

- It is **easy to talk** to the doctor
- There is **timely support**
- You **know your rights**



People do not feel in charge of their health when they

- **Feel unsure**
- Have **no choice**
- **Feel disrespected**

People said that doctors' visits could be made better.

- **Before visit** could be better if the waiting room were nicer
- **During visit** is better when the doctor listens and speaks at a good pace
- **After visit** is better when people have easy read notes to take away.



Closing Comments



People with learning disabilities want to be able to talk easily to their doctors.



We have the right to know what is happening to our bodies and to feel looked after.

Authors

IRN Steering Group (2019-2022)

Michael Sullivan (Chair)



Derek Murphy (Vice Chair)



Brian Donohoe (Secretary)



James Delaney (Vice-Secretary)



Carol-Ann O'Toole (IRN Spokesperson)



Christina Burke (IRN Vice-Spokesperson)



Kathleen McMeal (Treasurer)



Helen O'Regan (Vice-Treasurer)



IRN Members (in order by first name)

Aine McDermott



Joan Body
(Research Leader)



Breda Cross



Kathleen O'Leary



Brian Hogan



Laura Murray
(Research Leader)



Bridget Killeen



Lisa McHugh



Bridget Warde



Malachy McManus



Caiomhe McMahon



Martin Dooher



Cian Gurney



Michael Fitzgerald



Claire Nagle



Nancy Leddin
(Research Leader)



Dylan Moloney



Orla McMahon



Emer Hynes



Pauline Skehan



Fionn Angus
(Research Leader)



Rachel Kelly



Ger Minogue
(Research Leader)



Ruth Costello



Greg Singleton



Shane Brennan



Helen Nagle



Sophie Jacobsen



Jack Walsh



Jess Howard



Academic Supporters

Edurne Garcia Iriarte (TCD)



Nancy Salmon (UL)



Nicola Maxwell (UCC)



Supporters

Carmel Brady



Carolyn Gannon



Frieda Bent



Marcella Thorne



Marian Spelman



Marie Dillon



Mary Barrett



Michael Doolan



Nicolle Moloney



Jackie Moran



Jonathan Angus



Rob Hopkins



Sarah Meek



Sheelah Flatman Watson



Sheila Ford



Sonja Wolski



Research Assistants

Lorraine O'Hara (UL Student)



Orlaith McAuliffe (UL Student)



Roisin Stakelum (UL Student)



Thank you Notes

There are many people who made this research possible. We thank all of them for their time and support:

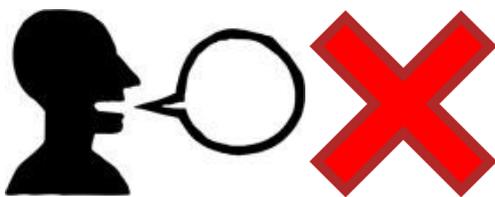
- The IRN Steering Group (2016-2019) who made key choices about this project: Nancy Leddin (Chair), Joan Body (Vice Chair), Brian Donohoe (Secretary), Laura Murray (Treasurer), Fionn Angus (Spokesperson)
- The 69 people who shared their time and stories about going to the doctor.
- Supporters who helped the people in focus groups speak up for themselves.
- Services who let us do focus groups at their sites.
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 - Brothers of Charity, Clare
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 - KARE
 - National Learning Network
 - Western Care
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- Special thanks to the IRN members who posed for photos used in this report. Other photos were sourced from creative commons.

Words We Use

Note on the Words We Use in this Report



The Inclusive Research Network has talked a lot about the words we use to tell people about our work.



One of the terms that is used often in Ireland is 'people with intellectual disability.' This phrase is not easy to say or easy to read.



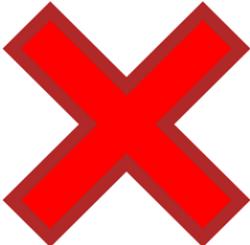
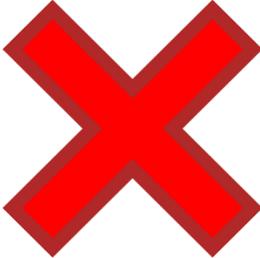
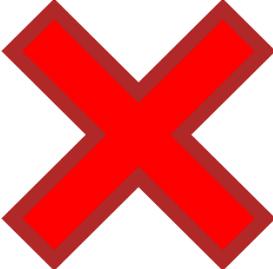
In talks by the IRN we often say 'IRN members' or 'self-advocates' when we refer to the people who are part of the IRN. In this report we agreed to use the term 'self-advocates' when we are talking about the IRN members with disabilities.



Many services in Ireland have agreed on new terms to use. For example, some services now say 'people supported' and others say 'people with extra support needs.'



When the IRN is applying for funding we have to explain who is part of the team in a way that is easy for review panels to grasp.

	<p>We came up with four options of words we could use to describe who we are:</p> <ol style="list-style-type: none"> 1. People with intellectual disabilities 2. People with learning difficulties 3. People with cognitive impairments 4. People with learning disabilities
	<p>We said 'no' to the use of 'people with intellectual disabilities' because everyone in the IRN cannot say this easily.</p>
	<p>We said 'no' to the use of 'people with learning difficulties' because members of the IRN did not want to be linked to the term 'difficult'. That term is always used in a bad way.</p>
	<p>We said 'no' to the use of 'people with cognitive impairment' since few in the IRN heard of this term and did not know what it meant.</p>
	<p>IRN members were not keen on any of the choices. Since we need to have a way to tell people who we are, in the end IRN members said 'yes' to 'people with learning disabilities'. We are so much more than what this label says about us.</p>



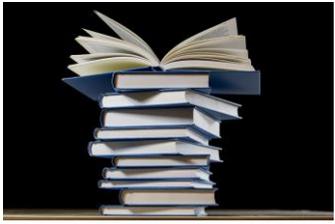
We are brothers and sisters, aunts and uncles, sons and daughters, researchers, colleagues, workers, authors, film makers, Irish Citizens, Olympic athletes, lobbyists, friends.



We will keep talking about this. One day we hope that we can stop using these labels.

There are a lot of research words in this paper. We wrote out what some of them mean below.

Photo	Research Word	What it means
	<p>Average Age</p>	<p>We talk about the ‘average age’ of people who took part in the project. Some people were much older than this age and others were much younger than this average age. We found out the average age by adding (+) the ages of every person who took part then dividing (÷) them by the total number of people in the group.</p> <p>For example, if we have a group of 3 people whose ages are 33, 27, and 30, we first add them up: $33 + 27 + 30 = 90$</p> <p>Then, we divide the result by the number of people in the group: 3</p> $90/3 = 30$ <p>The average age in this group is 30.</p>
	<p>Inclusive research</p>	<p>Inclusive Research is research done by people with learning disabilities with support from others. In inclusive research, people with learning disabilities think about the research, take part in doing the research and telling others about their research.</p>

	<p>Piloting Questions</p>	<p>Piloting research questions means that we ask the questions to people with learning disabilities before we do the research. This helps us know if the question makes sense and gets people talking.</p>
	<p>Numbered Sources</p>	<p>In the opening section of this report and in the links to other research you will see little numbers after some full stops. This is how we show that the words are supported by another researcher or team that wrote about their work. The full list of sources is in Chapter 9 at the end of this report.</p>
	<p>Research Leaders</p>	<p>In the author list there are 4 people who have the title of Research Leaders. These people are all past members of the IRN Steering Group (2016-2019): Nancy Leddin, Joan Body, Fionn Angus and Laura Murray. They all share what they learned while on the IRN Steering Group with others by giving peer support, doing talks, co-writing research reports and co-leading IRN working groups.</p>

Chapter 1: Opening

What is the IRN?



The IRN is a group of researchers who do research that is important to people with learning disabilities in Ireland.

What is this book about?



This book is about what it is like for people with learning disabilities in Ireland to go to the doctor.

It is called 'Doctors and Us'.

Why do we care about doctors' visits?



- People with learning disabilities have poorer health than people without disabilities.^{1,2} They face barriers to good health care such as access to buildings (physical), not being respected (social), and language issues (such as doctors using big words).^{1,3}



- A big Irish study about aging (IDS-TILDA)⁴ found that 1 in 3 adults with a learning disability have trouble making themselves understood when speaking with health professionals.



- There is a small amount of research about what it is like for people with learning disabilities to visit the Doctor.



- Most studies are about what doctors, family or support staff have to say.
- Five studies used some form of inclusive research ⁵⁻⁹.
- Only 2 of these were done as full partners or led by people with learning disabilities.

Why did we do this research?



We wanted to

- Share the stories of people with learning disabilities when they go to see the doctor.
- Find ways to help people feel more at ease at doctor's visits.



Chapter 2: Steps the IRN Took to do This Project

In 2016

Research theme



We started our project in Spring 2016 when we talked about research ideas.

We talked about many ideas. For example: work, education, money and health.

After 5 meetings we took a vote and agreed on the topic of “**Doctors and Us.**”

Looking at other research on this topic



We looked at what other researchers had written about people with learning disabilities going to the doctor.

We wanted to build on what others were doing.

A student at the University of Limerick helped us do a detailed search.

Choosing to do focus groups



We agreed to use **focus groups** to find out what it is like for people with learning disabilities to see their doctor.

We chose our questions and found pictures to get people talking.

In 2017

Ethical approval



We have ethics approval from University of Limerick to do our project. The approval number is: **EHSREC 2017-10-16**

Piloting our Questions

We tested our draft focus group questions. We asked people about



1. Choosing their doctor
2. Making appointments
3. Getting health checks done
4. Going to appointments on their own or with support
5. Ways to make visits better.

Creating Handbook

We made a 3 part book for IRN researchers that included:



A. Before the focus group

- What to do before a focus group like how to tell people about the project. This book had information sheets and consent forms for people to sign if they wanted to take part



B. Co-leading the focus group

- What to do on the day of the focus group. This book had all the questions and pictures to get people talking.



C. After the focus group

- What to do after the focus group like writing up notes of the key points and sending the consent forms and audio to the IRN secretary.

This 3 part book is posted on our website:

http://www.fedvol.ie/Inclusive_Research_Network_IRN/Default.241.html

Learning to Co-Lead Focus Groups



We had 3 training workshops during our monthly IRN team meetings to practice:

- going through consent forms with people
- co-leading a focus group
- using the audio recorder

IRN researchers used the handbook to practise co-leading focus groups

From 2017 to 2019

Co-Leading Focus Groups



15 IRN researchers co-lead focus groups with 7 supporters and 2 academics.



- All focus groups were audio-recorded.
- A note taker wrote down the main points people talked about.
- These notes were reviewed at the end of each focus group to check that we knew what people wanted to say.

From 2018 to 2019

Making sense of the data



- Co-researchers gave focus group recordings to the IRN secretary at monthly meetings,
- Recordings were then deleted by IRN co-researchers and supporters as part of our ethics agreement.



- Co-leaders wrote up notes from each focus group
- They gave these notes to the IRN secretary



- The IRN secretary and one academic supporter read the notes, then met up by skype to find what people had in common across focus groups.

- We met 4 times for 2 hours each session.

- We color-coded all the notes



- 2 IRN members, one supporter and one academic met by skype to go over all the color-coded ideas

- We met for a total of 3 hours and agreed on key quotes to show the main points.



- We created powerpoint slides to show our early findings in 4 talks in 4 different countries: Canada, Denmark, Ireland and Scotland



- Two students from University of Limerick typed up the focus groups.

- When typed up, each focus group was about 50 pages long.



- One of the university researchers went over all the typed pages to be sure what people said was typed correctly.

- She also checked to be sure all personal details were taken out of the pages.

In 2019

Writing this book



- We agreed on the key points from the focus groups
- We wrote them down in this book
- We chose the quotes that best suited the main points
- We read sections out loud and made changes so it was easier to read.
- We chose the pictures that best showed the main points.

Note to Readers

To make this book easier to read the quotes from participants are included in coloured boxes in the report.

You will see the use of **blue font** in some of the quotes. This means that there was a word we had to change to protect the person's privacy. For example, if someone said the name of a support person we put in **support staff** instead. If they talked about a certain place, we put in **town** instead.

Sometimes when we talk, we leave out words. To make sure the meaning of quotes is clear we also used **red font** when we put in a missing word.

Chapter 3: Who took part?

Men and Women



Age



In this section, we talk about who took part in the focus groups

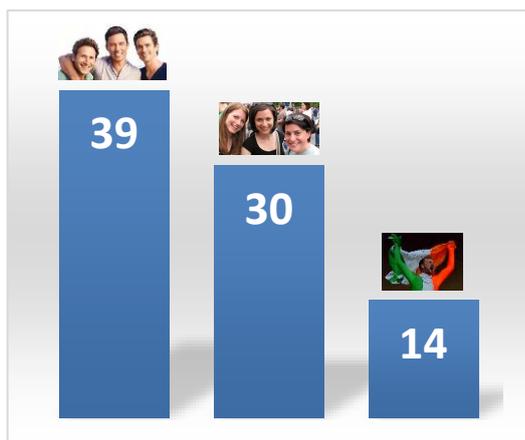


All people who took part went to a meeting where they learned about the project.

Each person took away a consent form to review.

Those who wanted to take part signed the consent form and brought it with them to the focus group.

Men and Women



We talked to 69 people with learning disabilities:

- 39 men
- 30 women

14 supporters also took part.

Supporters only talked when asked to do so by a person with a learning disability.

Age



Their average age was 45 years.

The youngest person we talked to was 20 years old and the oldest person we talked to was 70 years old.

4 people did not tell us their age.

Number of people in each group



The smallest focus group had 5 people in it.

The biggest focus group had 13 people in it.

Time for each group



Focus groups were all 1 to 2 hours long.

Chapter 4: What We Learned

Feeling Looked After



Taking Charge of My Health



Making Doctors' Visits Better



We asked people



We heard what it was like at the doctor's surgery and what it felt like to talk to the doctor.

We asked about:

- Going to the doctor on your own.
- Going to the doctor with support

What could make doctors' visits better for people with learning disabilities

There were 3 key findings from our study



Finding 1

People **feel looked after** when

- The doctor's office is **easy to access**
- they **feel welcome** and
- **feel at ease**

Finding 2

People **feel in charge** of their health when:

- It is **easy to talk** to the doctor
- There is **timely support**
- You **know your rights**

BUT people **do not feel in charge** of their health when they

- **Feel unsure**
- Have **no choice**
- **Feel disrespected**



Finding 3

People said that **doctors' visits could be made better.**

- **Before visit**
- **During visit**
- **After visit**



What people said: Key Finding 1



Feeling Looked After

Most people we talked to were happy with their doctor and felt well looked after during visits.

For example one person said,

3

"I'm happy with my doctor, I'm fond of my doctor I really am. They do their best, They keep us alive. That's the way I look at it."

People talked about feeling looked after when going to the doctor.

Feeling looked after happened in 3 ways.

1. **Easy Access.**

One person said, “



Having a bathroom that is easy to access with the wheelchair.”

Even when there is a ramp, it did not mean a surgery was easy to access.



One person told us about a portable ramp that did not work well, Because the ramp was not always there, this person chose to change doctors.

“A ramp pulls out in and I’m not happy. And then I moved to a new doctor and I can get in.”

2. Feeling welcome.



This was nicely described by one supporter who said,

“Girls at reception give the person a big welcome and a big goodbye on the way out.”

3. Feeling at ease mattered a lot to people we talked with.



People felt most at ease when they knew their doctor well and felt listened to.

It also helped people feel good about their visit when the doctor talked to them.

One person said,

“The doctor was lovely. He didn’t speak to the staff he spoke to me.”



Many people spoke about simple things that could make them feel at ease while waiting for the visit. Having a comfortable waiting room with books, TV, music and tea would help them pass the time while waiting to see the doctor.



There were some concerns about physical contact. Doctors were advised to ask before touching a person:

“Does the doctor ask permission to touch you? He should ask first before he touches you.”

What people said: Key Finding 2



Taking Charge of My Health

3

There were 3 main ways people felt they were in charge of their own health.

1. When **booking appointments**, people felt in charge of their health. Some people had support to set up appointments while others found that contacting the doctor on their own felt good.

One person said,

“You’re independent and you want to look after the doctor’s appointment yourself.”

2. People talked about **speaking up for themselves**.

One person said,

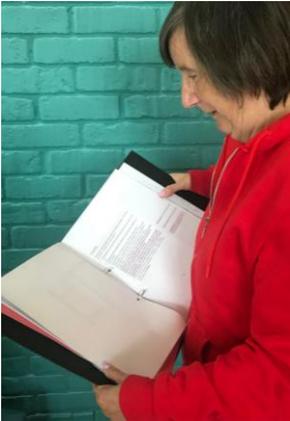
“Always update the doctor yourself about what is happening for you.”

Another person added,

“Don’t be afraid when you go in. Speak up and make sure you’re understood.”



3. Handling health details was talked about, with one person saying when they go to the doctor



“When I see my doctor I take my own file.”

This showed they were in charge.

Many people also talked about taking notes during the doctors visit to help them recall what the doctor tells them. One person said they jot notes into a file on their phone to review with a supporter after visiting the doctor.



Taking Charge: What Helps

There were a number of things that helped people take charge of their own health.

First was being able to **talk easily to the doctor**.

One person said,



“I know the doctor very well so I just go in and talk to him.”

Another person added,

“They talk to me – they try to explain it the best they can.”

Having **timely support** also helped people take charge.



One person told us,

“I prefer to go on my own but I sometimes get support when I need it.”

It was also important that **people knew their rights**.

One person said,



“You have the right to stay in the doctor’s office when he or she explains bad news to your staff or family.”

It also was important for doctors to know about these rights. The notes from one focus group summary stated,

“Doctors need to know that people with disabilities are entitled to know what is happening to their bodies.”



Taking Charge: What gets in the way

3

There were 3 main things that could get in the way of people taking charge of their own health.

1. Many people talked about **feeling unsure**. They were afraid to talk up, worried they might forget what was said.



When a person didn't know the doctor or did not feel sure about why they were seeing the doctor it made things harder for them.

One person told us,

I'm just afraid I'd forget what they say or not understand.

2. Having **no choice** about their doctor or when to talk to the doctor also got in the way.



One person told us

"I am not allowed to call doctor—only staff can."

3. People spoke about feeling they were **not respected** during doctors' visits in terms of privacy or when the doctor did not talk to the person.



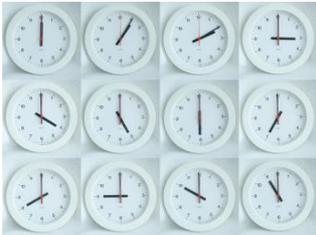
One person said,

"I had to go to the doctor recently. I only had my trousers and bra on and Doctor only pulled curtain and a bit It felt uncomfortable for me."

What People Said: Key Finding 3



Making Doctors' Visits Better



The third main point from our focus groups is about how to make doctors' visits better.

People had ideas about what to do **before**, **during** and **after** doctors' visits.

Before the Visit

Before the visit it would help if the person were involved in agreeing on the appointment time. Making a time that suits the person and being sure the person knows well ahead were noted.



One person said,

it was important, "to always be told when an appointment is made for you by staff well ahead."

Another person said,

"Be honest for yourself – speak up and say if you can't make the appointment when you have something else on."



People also wanted to have less waiting time when at the doctor's office and have a better waiting room.



People wanted doctors to know about key issues for people with learning disabilities.

One person said,

"Doctors should gather research about us, to understand us better, to be informed and involved."

During the Visit

During the visit, people wanted the doctor to show that they were listening and to speak at the right pace.



One person said,

"Meet face-to-face so you can ask doctor things for yourself."

Another person added,

"If doctor talks more gently...not too fast...say 'slow down'."



Some people may need more time to explain their story to the doctor. For example, one person said,

“the doctor needs time to figure out how the health has been. So [the person] needs time to tell the doctor every detail”

Having a range of tools to help the person and the doctor talk to each other was advised.



One person gave this example.

“Let’s say the doctor is talking to the person but... let’s just say the person had autism... the doctor should have pictures. For example, if you have a headache, there could be a photo of a person with hands on their head.”

People with learning disabilities were encouraged to stay calm during doctor’s visits. One person said,



“The thing about doctor, when you go into the doctor, you need to be cool and calm, see. If you get excited, it doesn’t help.”



People wanted to be treated with respect.
One person explained,

“Even if when you were walking in and they gave you a handshake and said ‘Oh, Hi Mary, do you mind if I give you a check-up?’

After the Visit

After the visit people wanted to have easy read notes and leaflets to help them remember the details about the visit.



One person told us,

“If you can’t read the doctor’s writing you can ask him to write it clearly.”

Another person added,



“Yeah, get [the doctor] to repeat it. Or give you a document, a page, a written supplement.”

Others suggested that the person write their own notes on paper or record key points on their phone to help recall what the doctor said later on.

Chapter 5: Links to Other Research

Doctors and Us



Feeling Looked After



Taking Charge of My Health



Making Doctors Visits Better

In this chapter, we talk about how our findings are linked to research done by others

Finding 1: Feeling Looked After



Easy Access is a big part of the United Nations Convention on the Rights of Persons with Disabilities.¹⁰ The Convention says that people with disabilities have the right to access buildings like hospitals and doctors' surgeries.



Access to information is also written into the Convention. This includes signs and health leaflets in easy read format for example.

A study in the UK said that in most doctors' waiting rooms:

- health leaflets were not easy to read and
- rarely had pictures to help people know what the text was about.¹¹



An even bigger link to Doctors and Us is **Article 25 of the Convention**. This means that people with disabilities have **equal access to health services** as people without disabilities.



Other researchers also found that knowing and trusting the doctor helps people **feel at ease**.¹²⁻¹⁵



Keeping to time can help many people with learning disabilities stay relaxed and get the most from the doctor's visit.¹⁶



Having good support during a doctor's visit helps both the person and the doctor feel at ease when talking to each other.¹⁷

Finding 2: Taking Charge of My Health

What Helps People Take Charge



Health checks started in the UK in 2006. It was hoped that health checks would give equal access to health services to people with disabilities.^{11, 18}



A large project looked at all the studies done about health checks.¹⁹

They found that when health checks were done each year doctors were able to find many health conditions that could be treated.



Another study in Australia found that when people had health checks done

- they were more likely to do things to support their own health and
- doctors paid more attention to the health needs of people with learning disabilities.²⁰



Right now there is no system for health checks in Ireland for people with learning disabilities.

What gets in the way of people taking charge



Other researchers found that many people feel nervous when talking to their doctor.^{12-15, 21}

Some people worried that the doctor would have trouble knowing what they were saying.^{12, 13}



Like those who took part in Doctors and Us, people in other studies said that they were not happy when doctors talked to the supporter instead of them.^{14, 22}



Having only a short amount of time to talk to the doctor also got in the way of good healthcare.²²

Making Doctors' Visits Better

Before Visit



A study done in Scotland said that people with learning disabilities and support staff were concerned about long waiting times at the doctors' surgery.²¹

This supports our finding that people want to keep waiting times short at the doctors' office.



Another study said visits went best when doctors

- took more time to prepare for the visit and
- understood the unique needs of the person.²³

During Visit



One study we read said that people with learning disabilities can find it hard to tell the doctor exactly how they are feeling. Others say it is hard to recall the details about their health when they see the doctor.¹²



Doctors agree that getting the full health story during a visit can be hard.^{15,17}

Doctors felt unsure about how much of what was said in the visit was understood by people with learning disabilities.^{12,13}



Both doctors and people with learning disabilities agree that a visit takes longer when they really listen to each other.^{12,13}

After the Visit



Having easy read papers to take away helped people understand their health issues better.²³



We did not find any research that talked about people with learning disabilities taking their own notes or recording what the doctor said on their phone.

We think this is a great way for people to take charge of their health.

Chapter 6: Key Messages

For people with learning disabilities



For Doctors



For the HSE



**For Families and
Supporters**



In this chapter, we offer advice based on our findings. We also explain what the United Nations Convention on the Rights of Persons with Disabilities has to say.

The United Nations Convention on the Rights of Persons with Disabilities (the Convention) says what countries have to do to make sure people with disabilities have the same rights as everyone else. There is a long list of rights in the Convention. They are all important. We need to know which rights in the Convention are important for people with learning disabilities going to the doctor.



IRN Advice to people with learning disabilities

You have rights that include:

- The right to easily get into the doctor's surgery whether you walk or use a wheelchair.
- The right to have privacy about your health
- The right to keep, give and receive information about your health
- The right to support during appointments, when it is needed
- The right to choose and/or change your doctor
- The right to respect during the doctor's visit.
- The right to see a doctor in the community





It is ok to feel unsure or nervous about seeing the doctor. Try not to feel too worried. Stay calm.

Speak up for yourself.



This includes taking charge of booking your doctor's visit.

- You can call the doctor yourself or ask for support to book the visit.

It also means to let the doctor know if you need to cancel.

There are lots of things you can do to help recall what the doctor says to you.

- You can take your own notes
- Ask the doctor or your support person to write down key points
- Ask the doctor if you can record what they say on your phone.



Article 12 of the Convention is about being treated equally by the law.

- People with disabilities, like everyone else, have the right to make decisions. They have the right to get the support they need to make decisions
- People who work in services, like health, need to understand that the law says everybody has the right to make decisions.
- People have the right to get information in a way that is easy for them to understand.



IRN Advice to Doctors

Before the Visit



The doctor's surgery needs to be accessible,



Find ways to help people relax while they are in the waiting room.



The people working at the doctor's office should be friendly and polite.



Doctors need to know that people with learning disabilities have rights.

That means doctors might need to learn how to talk and write in different ways to give people with learning disabilities the information they need about their health.

During the Visit



Sometimes people feel unsure when they are talking to you. People might need more time to explain about their health.



The doctor and the person need to respect each other during the visit.

One way to show this is to speak to the person rather than to the supporter



It would be great for doctors to have a set of pictures that they could use when people have trouble talking. For example, you could use emojis to help people explain how they are feeling.

After the Visit



Be flexible about how a visit can be improved. For example, some people might find it helpful to record your advice on their phone.



Doctors could get notes typed up to make it easier for the person to read since handwriting can be hard to read.

Article 19 of the Convention is about the right to live in and be part of the community. It says that people have the right to access health services where they live.

Article 22 of the Convention is about respecting and protecting privacy. People with disabilities, like anyone else, have the right for their personal information to be kept private.



Set up a health check system for people with learning disabilities in Ireland.

In the UK they use health passports. The IRN would be happy to work with the HSE to design something like this to use in Ireland



Build in more time for doctors to spend with people with learning disabilities who may use pictures instead of words to explain how they are feeling. It could help if the HSE paid doctors for the time they need to spend to treat people with learning disabilities equally.



Support doctors to learn how to talk easily and listen to people with learning disabilities.



Work with a group of people with learning disabilities and doctors to create easy read leaflets about common health issues. For example: diabetes, heart health, drug and alcohol use, sexual health.

Article 25 of the Convention says a lot of things about health services and people with disabilities like:

- people with disabilities have the right to access and use health services the same as everyone else.
- people with disabilities must be treated equally when they use health services, like the doctor's surgery.
- people who work in health services need training in human rights so they know that people with disabilities have the same rights as anyone else.



IRN Advice to families and supporters



Support people to contact the doctor when they want to book a time to see the doctor.



Before a doctor's visit check with the person to see what would make them feel most at ease



Ask if the person with a learning disability wants you to go in to see the doctor with them or if they want some privacy

If the doctor starts talking to you instead of the person you are there to support, ask the doctor to talk directly to the person.



Ask if the person you support wants you to write down a few notes to help them remember what the doctor says during the visit.



It is good to talk to the person before the visit using pictures for them to explain how they are feeling.

For example, you could use emojis to show happy, sad, worried, anxious, headache, eyes, throat, chest, ears, back, stomach, fever, pain.

Chapter 7: IRN thinking back on the project

What went well?



What could we do better?



In this chapter, we talk about what went well and some of the things we could do better next time



The quotes below show what IRN members said that went well in the Doctors and Us project

Inclusive research keeps people with disabilities in touch with what the issues are

I found [the project] easy from the start. [My supporter] explained it to me and anytime I had questions or found things tricky I always got answers. The ethics form wasn't too bad

Gives people more confidence to talk up themselves

[It's good to] hear what they think about problems they have

I was happy there was an easy read consent form and a consent quiz

Meet and get to know new people from different counties in Ireland

It went well in focus groups. I found it all right.

learned new ideas, heard other people's experiences, now i will ask more questions,

I feel less nervous about visiting the doctor now.

The quotes below show what supporters had to say about things that went well with the project

I agree that [ethics] was complex at first, but after we talked about it over a few weeks we were able to break it down so that everyone was comfortable. Talking about it in small groups helped

everyone gets a chance to say what they think.

It's great to have easy read forms

[It is good] to be with a group of people who were able to express themselves freely and knew what they want to say.

[It is helpful to] have it broken down so that everyone can understand. [The university researchers] take the time to explain.

Having the 3 books to explain what to do before, during and after the focus groups helped us so much. We could just check the book to be sure about what we were meant to do at each step of the project.

Supporting the group to develop their interview skills and understanding of the research process while exploring the question at hand was a pleasure. The people who took part appeared to grow in confidence and engagement as they gained an understanding of their roles, especially the focus group leaders.

The IRN is a powerful, strong group that I'm privileged to sit in on. Personally, I learn new skills and information that I use to support researchers but also in my role in services.

University researchers told us what they found went well in Doctors and Us:

People were so keen right from the start of the project. We worked hard to agree on the research topic and to design all the focus group questions.

A working group met every week during the summer of 2018 to go through all the focus group summaries and to agree on key findings. We did this over skype which was a great chance to get us all to work from places in Ireland, Spain and Canada. That was a lot of fun.

We have been sharing the findings of this project with people since the middle of 2018. Each time a new set of people did the talk, making it their own. The number of people in the IRN who have now done talks is amazing! One of the talks was even live streamed, so I was able to see the talk from Canada. That was GREAT!

Peer support is becoming the norm in the IRN as IRN members with more experience support new members to do talks about our work.

Having IRN members go to new places, like UCC, and explain what they do and about the Doctors and US project was great. This meant that new people, especially people with learning disabilities, found about the IRN and the research project. It also meant that more people found out about the IRN and the work it does.

What could we do better?



We learned so much about working together during this project. We are all very proud of what we were able to do. It is always good to think about how we can build on this success and agree on what we could do better in our next project. Here are some ideas from IRN members.

We need to be careful how we say things so that we explain things in ways people can understand

The ethics application form was a bit complex

It takes a long time to finish projects.

Have more focus group sessions and do more roleplaying as it is fun.

It can be hard to express exactly what you would like to say

We need more supporters for the IRN to keep going

Some words about research are difficult to explain and to understand

No IRN members are paid. Only supporters are paid supporters. The IRN secretary is paid 1 day per week by the National Federation of Voluntary Service Providers

Supporters had these things to say about what the IRN could think about ahead of our next project.

There were no supporters at the largest focus group. Though I knew all the participants. Word went round the centre and they were all keen to join in. It worked quite well in spite of the size.

I found it difficult to direct the focus group responders to the leaders as I knew many of them through my work and they tended to direct their answers to me when responding. Possibly supporting other advocates outside my own group might help in future.

It was difficult to get a focus group together because everyone had their own time tables that were quite full with activities such as work, swimming and gym visits. A good complaint, but it made it challenging to find a time to suit all for our focus group work

The skill of enabling all views to be expressed around the focus group participants and try to manage strong personalities from speaking on behalf of the group and therefore dominating ideas expressed is a tough one for co-leaders and supporters. I have found it to be a major challenge for all self-advocates with learning disability in leadership roles in self advocacy situations I have attempted to facilitate.

Focus group members were sometimes inclined to copy what another group member had said.

University researchers had ideas about what was hard about Doctors and Us. They also spoke about what we could do better in our next project.

It would be good if the IRN members could travel to other parts of the country to do their work. It does take time and effort to prepare for visits and get support. It would be great if there were supporters in more parts of the country, including universities, to support the IRN and maybe new members.

Having IRN members who were leading focus group but who also wanted to take part in focus groups was tricky to explain to the ethics committee and also to the IRN members

The IRN has been in place for over 10 years now. The group has changed and grown in so many ways. Yet we remain vulnerable. We need more supporters to keep the group vibrant.

We held several sessions to support people to co-lead focus groups. Two IRN members co-lead at least 3 focus groups. Most people co-lead one focus group. With all the time and effort that went into preparing to co-lead, it would be really good if people could have done this at least two times to build their confidence.

Competing for research funding is difficult for the IRN as research timelines are tight. We make decisions about research when we meet once a month. Funding calls are not in plain language and it takes us time to change into easy to read and to explain funding calls to the team.

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