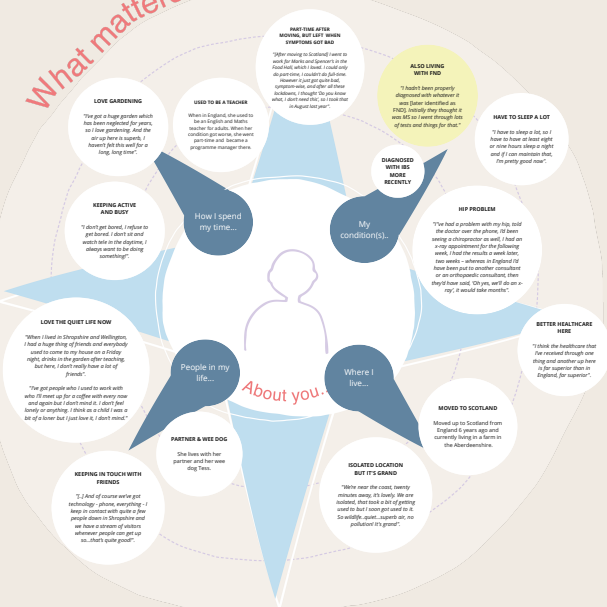


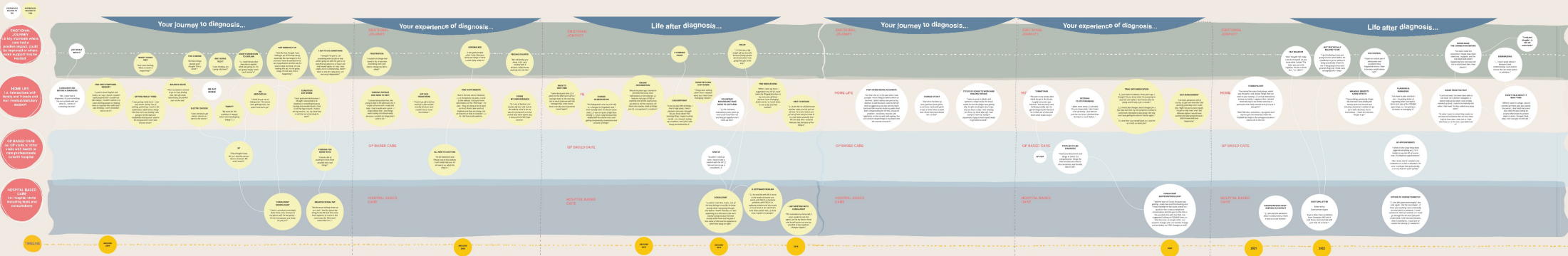
experience map  
*irritable bowel syndrome*

# Overview of all maps

## What matters to you?



## What matters to you? See in detail on page 3

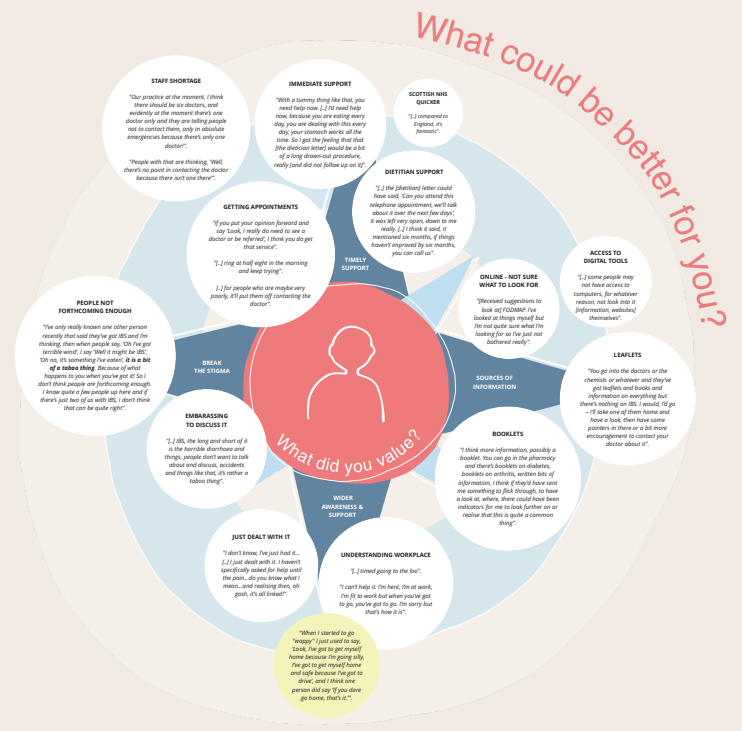


## Your journey (mainly focusing on FND) See each panel in detail on pages 4-5

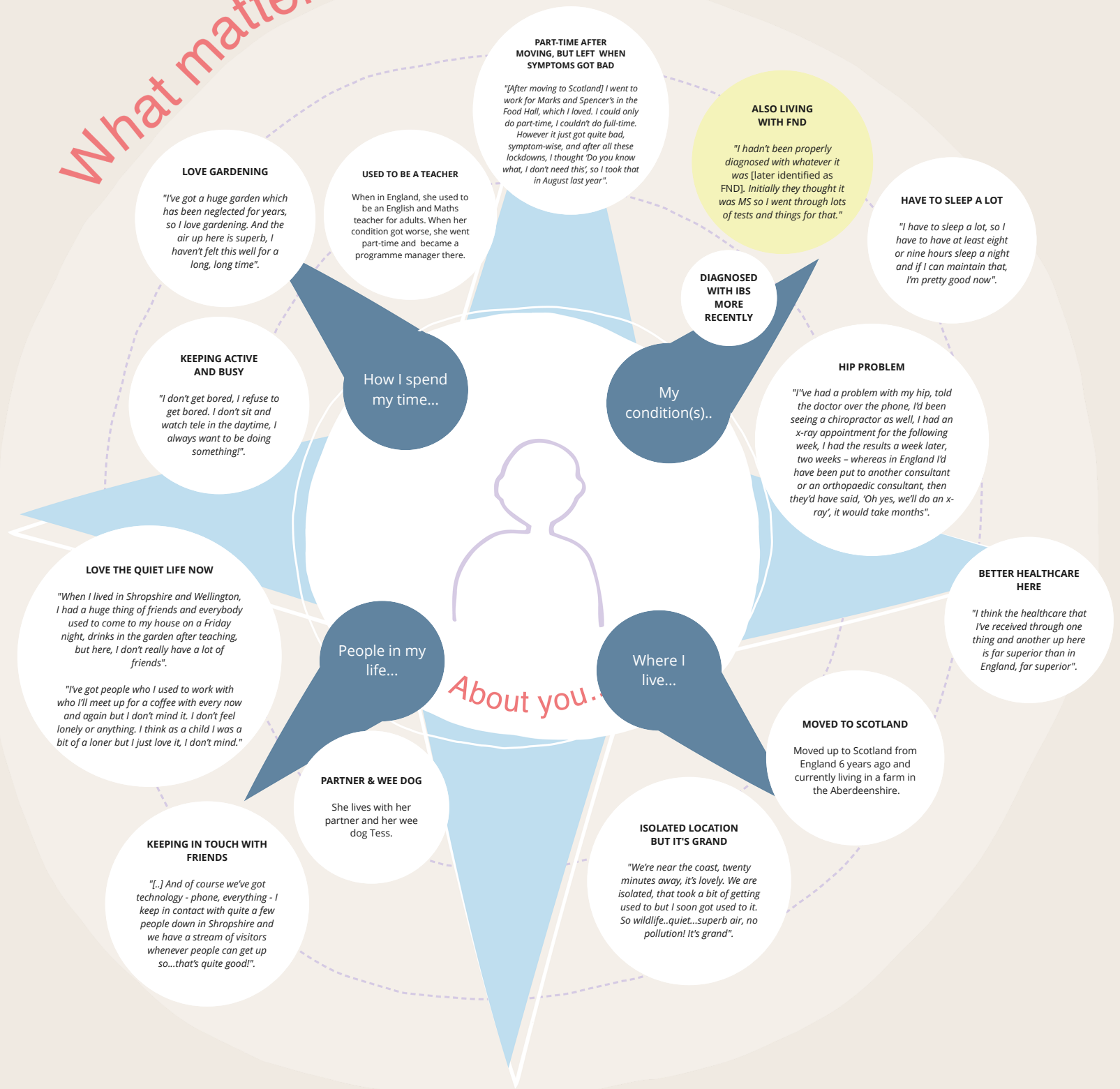
## Your journey (mainly focusing on IBS) See each panel in detail on pages 6-7

## What could be better for you? See in detail on page 8

## What could be better for you?



# What matters to you?



EXPERIENCES RELATED TO IBS

EXPERIENCES RELATED TO FND

# Your journey to diagnosis...

**EMOTIONAL JOURNEY**  
i.e key moments where care had a positive impact, could be improved or where more support may be needed.

**HOME LIFE**  
i.e. interactions with family and friends and non medical/statutory support

**GP BASED CARE**  
i.e. GP visits or other visits with health or care professionals outwith hospital

**HOSPITAL BASED CARE**  
i.e. hospital visits including tests and consultations

TIMELINE

AROUND 2004

**JUST DEALT WITH IT**

**WHAT'S GOING ON?!**

"And I was thinking, 'What on Earth is happening?'"

**THIS IS WEIRD**

"All these things started and I thought 'This is weird'."

**AM I GOING SILLY?**

"I was thinking, am I going silly here?"

**DIDN'T KNOW HOW TO EXPLAIN**

"(...) I didn't know then how else to explain what was going on, I'm just going 'wappy' and I can't control it".

**NOT MAKING IT UP**

"I felt like they thought I was making it up all the way along, especially the neurologist in the end and I think he wanted me to see a psychiatrist and the way he said it made me think, 'I'm not making this up, I'm not going loopy, I'm not nuts, this is happening'".

**I GOT TO DO SOMETHING**

"I thought I've got to...do something with my life to help what's going on with me, got to try and find out what it is or how I can help myself again, as I say, I was single, not in a relationship, hadn't been in one for a few years, so I was very independent".

**LIVING WITH IBS BEFORE A DIAGNOSIS**

"IBS, I never had it diagnosed, it's just something I've sort of dealt with, put down to...nerves or something like that".

**FND FIRST SYMPTOMS - MEMORY**

"I used to teach English and maths, as I say, I found I couldn't spell properly and I couldn't do take-aways, I couldn't subtract, so I was teaching people or helping them to improve their skills and I was thinking, I can't remember how to do it!".

**GETTING REALLY TIRED**

"I was getting really tired - I was very active, sporty, lots of walking, gardening, I used to like badminton, table tennis, things like that and I was finding I was going to hit the ball and completely missing and I used to be very good at it and I was missing shots!".

**BALANCE ISSUES**

"Then my balance started to go so I was finding that I fell off a bike, ridiculously, just keeled over on the side".

**IBS GOT WORSE**

**ELECTRIC SHOCKS**

"I was starting to get electric shocks so I went to the doctor".

**"WAPPY"**

"My word for this condition is 'wappy', when I feel myself going 'wappy' (...)

**ON MEDICATION**

"I think he put me on Gabapentin. The shocks were getting worse, my speech started to go".

**CONDITION GOT WORSE**

"I was quite worried because I thought I was going to be disabled or something because my legs just wouldn't work, I had to tell my legs to work. I had to tell my head to...no, my head had to tell the rest of my body to work".

**GP**

"They thought it was MS, so I had the various tests to check for MS and it wasn't".

**PUSHING FOR MORE TESTS**

"It took a bit of pushing to have more possible tests and things".

**CONSULTANT NEUROLOGIST**

"I had a consultant neurologist down there, who, because of my age as well, he was going... 'It's the menopause, you know, it's just you'".

**NEGATIVE SPINAL TAP**

"But because nothing shows up on a test, I had the spinal tap thing for the MS and that came back negative, of course it did, and it was like 'Well, don't know what it is...'"

# Your experience of diagnosis...

## EMOTIONAL JOURNEY

### FRUSTRATION

"I couldn't do things that I used to do, it was very frustrating and I just had to change my life to adapt".

### GOBSMACKED

"I was gobsmacked when I saw it because there was things in there I could really relate to."

### FEELING ISOLATED

"But still feeling you know, a bit...very isolated with it because I didn't know anybody else like this".

### CHRONIC FATIGUE AND NEED TO REST

"I started doing that then, like going to bed in the afternoon for a couple of hours and it really did help. I had to walk with a stick - I forgot about that - and things were looking a bit bleak really because I couldn't do things that I used to do."

### OFF SICK FROM WORK

"I had to go off sick from work for a few months actually because I just couldn't do it, it was horrendous".

### FIND HOPE WEBSITE

"And in the end, doctor Newman, [...] in Shropshire, he said [...] 'Look at this website, I've found some information on this 'FND Hope' - he said - 'They are doing a lot of work on this (I think it was north of England) and they are doing a lot of research on that in Scotland'. (...) So I did look at the website ..."

### DOING MY OWN RESEARCH

"So I sort of backed...not backed off, but I did look at the website, tried to do my own bit of research on it but at that time there wasn't any, it was just this FND Hope website".

## GP BASED CARE

### ALL NEW TO DOCTORS

"He [Dr Newman] said 'Please look at this website, I can't really help you, it's all new to us, what this thing is.'"

## HOSPITAL BASED CARE

AROUND 2008

# Life after diagnosis...

## EMOTIONAL JOURNEY

### A TURNING POINT

### RELIEF

"[...] that was a big weight off my shoulder because finally people who knew what I was going through, knew why".

### BACK TO PART-TIME

"I went back part-time [...] It gave me the afternoons off so I could go teach in the morning, not so much pressure with the managership, come home, have a wee kip and rejuvenate myself again".

### FE

### CHANGE IN MEDICATION

"The Gabapentin sent me a bit silly so I changed to Pregabalin and I have actually been on that for years now [...] I was on quite a high dose initially [...] four a day because they helped with the shocks and I was getting involuntary movements and all sorts of things".

### ONLINE INFORMATION

"About ten years ago I started to find that there was more information on the internet. [...] now you can pop in FND or anything and all this stuff comes up about it, all this research, all these case studies, loads of things and it's a recognised [...] condition".

### 50th BIRTHDAY

"It was my big 50th birthday, I had a huge party, I had a fantastic time and I thought 'Do you know what? This teaching thing, it wasn't suiting my life - no, it wasn't suiting my condition', and I felt it was being exacerbated by it".

### THING SETTLING A BIT DOWN

"Things were settling down since I stopped work, but I think I was managing it better".

### VOLUNTARY REDUNDANCY AND MOVE TO SCOTLAND

"[...] the voluntary redundancy posts came up and I took it and then me and Rod got together and I came up here".

### FND MEDICATIONS

"When I came up here, I suggested to my GP if I could lower the [Pregabalin] dose or try and come off them because I was managing better and [...] so I went down to one a day and that worked".

### REST TO RETUNE

"[...] it felt like an old-fashioned wireless radio, and it's just out of tune. For some reason you go out of tune and you have to try and retune yourself. And the one way that I could do that was rest. Because of the fatigue".

## GP BASED CARE

### NEW GP

"So when I came up here, I had to have a medical with the GP [...] She sent me to see a consultant [...]".

## HOSPITAL BASED CARE

### CONSULTANT

"[...] when I met him, it was...one of the best feelings in my life: he knew exactly what I was going through. And before I hadn't had this, so I was explaining it to him and in the end I started crying because he knew exactly what it was and he gave it this name of FND and he explained it which was bang-on right".

### A SOFTWARE PROBLEM

"[...] he said like with MS it starts in the head and works outwards, with MS it's a hardware problem, with FND, it's a software problem and that made a lot of sense to me. And that's how, when people ask [...], that's how I explain it to people".

### LAST MEETING WITH CONSULTANT

"The consultant up here said if I ever needed to see him again, just let my doctor know and he will see me as soon as possible, if any negatives changes happen".

AROUND 2012

AROUND 2016

2018

## Your journey to diagnosis...

### EMOTIONAL JOURNEY

### HOME LIFE

#### PAST HORSE-RIDING ACCIDENTS

"I've had a lot of, in the past when I was younger, horse-riding accidents which at the time, I didn't realise, was part of my balance as well because I used to fall off and I've jiggered up my hip and my lower back and the muscles inside my pelvis had been compensating for all this, structural problem - my bones, muscles and ligaments, so that as well, with ageing, has sort of done stupid things to my bowel and the muscles around it".

#### CHANGE OF DIET

"And since I've been up here, [partner] loves garlic, so we have meals with garlic in two or three times a week and I think that exacerbated this as well".

#### CYCLES OF GOING TO WORK AND HEALING FATIGUE

"I went to work in Marks and Spencer's, it kept me fit, the hours suited me but the fatigue was getting silly. So after working for four days, only six hours a day, I was sleeping for three, my three days off, I was trying to catch up, trying to rejuvenate, trying to heal myself ready to get back to work".

### GP BASED CARE

### HOSPITAL BASED CARE

## Your experience of diagnosis...

### EMOTIONAL JOURNEY

### HOME LIFE

#### TUMMY PAIN

"The pain in my tummy that made me go to the doctor, roughly two years ago, because I was worried, I was thinking possibly was it a gynaecological pain because it's in that sort of area and that's what made me go".

#### DECIDING TO STOP WORKING

"[After some time] [...] I decided, 'Do you know what, I don't need a lot of money, I just want to just live' and since I finished that I've been so much better..".

#### TRIAL WITH MEDICATION

"[...] just before lockdown, three years ago, I thought 'Do you know what, I'm just going to stop this one tablet, I don't know what it's doing and I'll stop it for a month'".

"[...] I had a few changes, weird changes for a few days but then my old symptoms started to come back. My balance was going a bit silly and I was getting the electric shocks again.."

"[...] and then I put myself back on it and I'm on it still, so that's fine".

#### SELF MANAGEMENT

"I do have symptoms still of course, if I get over-tired like I did painting yesterday and I could feel, 'Right I've got to pace myself, I've got to stop now', and I did. Whereas before I would have pushed and kept going because I didn't know what was happening".

### GP BASED CARE

#### GP VISIT

#### TESTS LED TO IBS DIAGNOSIS

"I had some blood tests and things to check, is it campylobacter, things like that and then we came to this conclusion, well she did, that it's IBS".

### HOSPITAL BASED CARE

#### CONSULTANT GASTROENTEROLOGIST

"[At] the start of Covid, the pain was getting...really bad and the bloating and it was making me feel quite unwell so I spoke to her, it was a telephone conversation and she got on the link or the possible link with the FND, she suggested looking at FODMAP diets, to help because, as we get older, our systems change a bit, our bodies change and probably our FND changes as well".

2020

# Life after diagnosis...

## EMOTIONAL JOURNEY

### FELT NEGATIVE

"And I thought 'Oh crikey, I can do it myself', do you know what I mean? The letter was just a bit negative, 'Oh let us know but...' so I didn't".

### NOT SPECIFICALLY RELATED TO ME

"I got the feeling it was just going to be an email with a list of websites to go to, without it being specifically related to me, it was going to be a very general thing and I think I was managing with it okay".

### NO CONTROL

"I have no control over it whatsoever and accidents have happened and so I have to be very careful where I go!".

### NEVER MADE THE CONNECTION BEFORE

"I've never made the connection. People have never asked me, I suppose, and I've only dealt with what's happening here and now and not so much back then. How bizarre".

"I only just thought - is this all connected?"

### EMBARASSING

"... I never spoke about it because it was embarrassing. I just used to choose the non-meat option or whatever."

## HOME

### FODMAP & DIET

"I've started the main food groups, which was the garlic, milk, bread, things that can react in your tummy [...] I sort of cleansed my tummy out really, I suppose, then I started reintroducing to see if there was any in particular that really reacted and of course it was garlic".

"With FND also, sometimes...my signals don't work or get a bit distorted, that's the FODMAP will help in dire emergencies when I need to do to the loo".

### WALKING: BENEFITS & SIDE EFFECTS

"I love walking, gardening, things like that and I was finding the tummy-ache and muscle and bloating relieved as I walked. If I go for a walk. But then, this is horrendous - I have this reaction, I've got to go".

### PLANNING & MANAGING

"I do have to plan a bit but I can - I'm getting better at regulating what I eat before that it isn't any of the FODMAP type things, so I am getting a bit better at managing it".

### ISSUES FROM THE PAST

"I can't eat meat. I've never been able to eat meat. I'm a farmer's daughter, it doesn't add up but when I was a baby, mashed up food, I used to be violently sick when I had meat. So they called me a fussy eater".

"So when I went to school they made me eat meat at lunchtime then an hour later, half an hour later I was sick or I had diarrhoea, so in the end, I just didn't eat it".

### DIDN'T TALK ABOUT IT BACK THEN

"[When] I went to college, I found another girl there who was exactly the same [...] And she'd had some tests that she was lacking an enzyme that broke the protein down in meat. I thought 'Yeah, okay', and I just got on with life .."

## GP BASED CARE

### GP APPOINTMENTS

"I think it's the Covid thing that's jiggered everything up [...] it is harder to see the GP, of course, now, it's telephone appointments".

"But I know that if I needed more treatment or a chat or whatever, I'm sure I could get that quite quickly, or in my head it's quite quickly".

## HOSPITAL BASED CARE

### GASTROENTEROLOGIST - KEEPING IN CONTACT

"[...] she said she wanted to keep in contact every, I think it was six to ten months".

### DIETITIAN LETTER

Referred by Gastroenterologist.

"[I got a letter from a] dietitian from Grampian NHS and it said 'If you need any help with your diet, let us know'".

### OPTION TO CONTACT DIRECTLY

"[...] she [the gastroenterologist] also said, again - like the neurologist - if there was anything I was untowardly worried about or whatever, I could contact her direct if I wanted, or I could go through the GP and I felt quite comfortable, I felt that was fantastic, that if I wanted to, I could sort of contact her directly if I needed to".

2021

2022

# What could be better for you?

## What did you value?

### STAFF SHORTAGE

"Our practice at the moment, I think there should be six doctors, and evidently at the moment there's one doctor only and they are telling people not to contact them, only in absolute emergencies because there's only one doctor!"

"People with that are thinking, 'Well, there's no point in contacting the doctor because there isn't one there!'"

### IMMEDIATE SUPPORT

"With a tummy thing like that, you need help now. [...] I'd need help now, because you are eating every day, you are dealing with this every day, your stomach works all the time. So I got the feeling that that [the dietician letter] would be a bit of a long drawn-out procedure, really [and did not follow up on it]".

### SCOTTISH NHS QUICKER

"[...] compared to England, it's fantastic".

### DIETITIAN SUPPORT

"[...] the [dietician] letter could have said, 'Can you attend this telephone appointment, we'll talk about it over the next few days', it was left very open, down to me really. [...] I think it said, it mentioned six months, if things haven't improved by six months, you can call us".

### GETTING APPOINTMENTS

"If you put your opinion forward and say 'Look, I really do need to see a doctor or be referred', I think you do get that service".

"[...] ring at half eight in the morning and keep trying".

"[...] for people who are maybe very poorly, it'll put them off contacting the doctor".

### TIMELY SUPPORT

### ONLINE - NOT SURE WHAT TO LOOK FOR

"[Received suggestions to look at] FODMAP. I've looked at things myself but I'm not quite sure what I'm looking for so I've just not bothered really".

### ACCESS TO DIGITAL TOOLS

"[...] some people may not have access to computers, for whatever reason, not look into it [information, websites] themselves".

### PEOPLE NOT FORTHCOMING ENOUGH

"I've only really known one other person recently that said they've got IBS and I'm thinking, then when people say, 'Oh I've got terrible wind', I say 'Well it might be IBS', 'Oh no, it's something I've eaten', it is a bit of a taboo thing. Because of what happens to you when you've got it! So I don't think people are forthcoming enough. I know quite a few people up here and if there's just two of us with IBS, I don't think that can be quite right".

### BREAK THE STIGMA

### EMBARASSING TO DISCUSS IT

"[...] IBS, the long and short of it is the horrible diarrhoea and things, people don't want to talk about and discuss, accidents and things like that, it's rather a taboo thing".

### SOURCES OF INFORMATION

### BOOKLETS

"I think more information, possibly a booklet. You can go in the pharmacy and there's booklets on diabetes, booklets on arthritis, written bits of information, I think if they'd have sent me something to flick through, to have a look at, where, there could have been indicators for me to look further on or realise that this is quite a common thing".

### LEAFLETS

"You go into the doctors or the chemists or whatever and they've got leaflets and books and information on everything but there's nothing on IBS. I would, I'd go - I'll take one of them home and have a look, then have some pointers in there or a bit more encouragement to contact your doctor about it".

### WIDER AWARENESS & SUPPORT

### JUST DEALT WITH IT

"I don't know, I've just had it... [...] I just dealt with it. I haven't specifically asked for help until the pain...do you know what I mean...and realising then, oh gosh, it's all linked!".

### UNDERSTANDING WORKPLACE

"[...] timed going to the loo".

"I can't help it. I'm here, I'm at work, I'm fit to work but when you've got to go, you've got to go. I'm sorry but that's how it is".

"When I started to go 'wappy' I just used to say, 'Look, I've got to get myself home because I'm going silly, I've got to get myself home and safe because I've got to drive', and I think one person did say 'If you dare go home, that's it.'".