



healthwatch
Wirral

**Believe in
children**



Barnardo's

Young Carers' Voice Focus Group

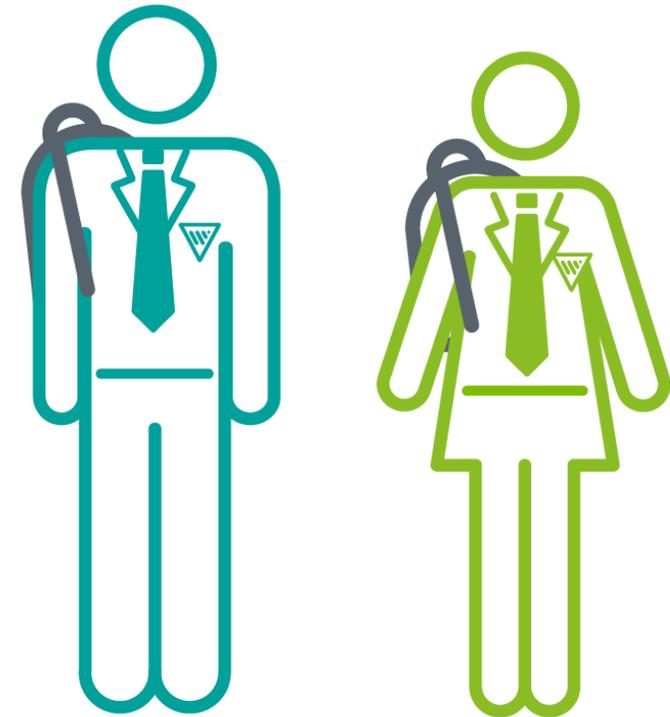
9th Dec 2021

Background – previous meeting

Healthwatch Wirral first met with a group of young carers from Barnardo's Action With Young Carers Wirral in February 2021 as part of our commitment to hearing from a range of voices about their experiences of health and social care.

The report from the February meeting is available at: <https://healthwatchwirral.co.uk/wp-content/uploads/2021/04/Healthwatch-Wirral-Young-Carers-Voice-Focus-Group-FINAL.pdf>

The young carers expressed an interest in continuing to work with Healthwatch Wirral: we organised a second meeting to discuss their experiences throughout 2021 and find out their priorities in terms of health and social care.



Who attended the group?

Jenny and Adam from Healthwatch Wirral facilitated the session, with support from Jackie from Barnardo's.

The young carers ranged in age from 11-13 and were all caring for a parent. Some had also previously cared for a grandparent.



What does Healthwatch Wirral do?

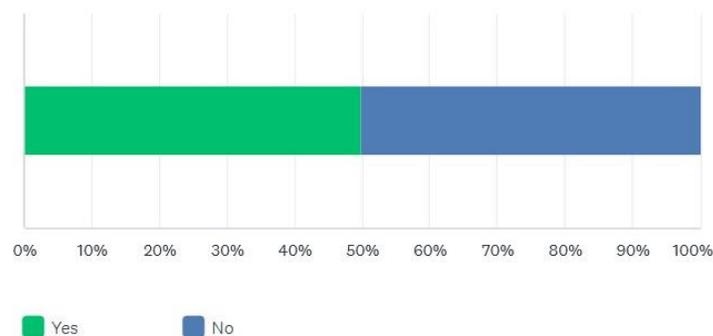
In a survey of young carers before the meeting, half of respondents had heard of Healthwatch Wirral (an improvement on our last survey when none of the young carers had!)

One young carer who had attended the February session was able to explain our function to the rest of the group:



“Don’t you want to know what’s going on and how we think – our perspective? So not only just data, but how people agree with that.”

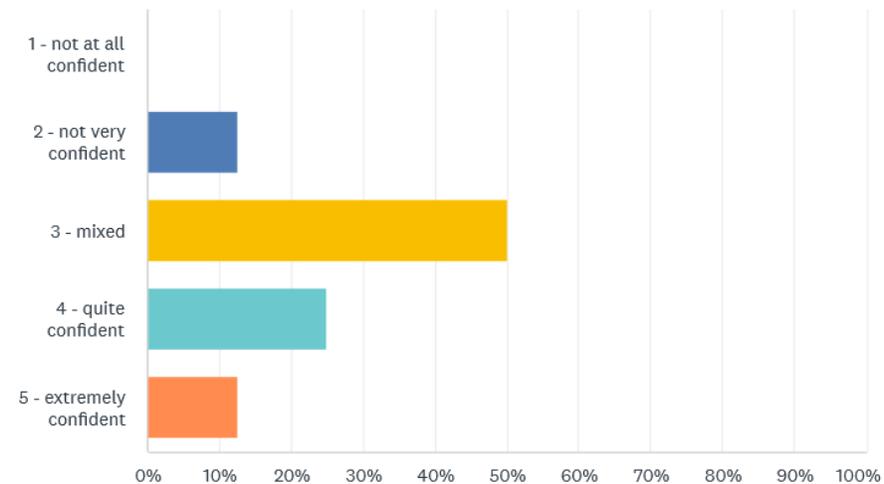
Had you heard of Healthwatch Wirral before being invited to this session?



Speaking to health and social care professionals

Young carers who answered the survey felt very mixed about speaking to health and care professionals. It is encouraging that more young carers rated themselves as confident or quite confident than as not very confident, but “mixed” was the most common answer, so Healthwatch Wirral wanted to use this session to dig deeper and find out more about their experiences.

On a scale of 1-5, how confident do you feel about speaking to a health professional (e.g. GP, dentist, optician), for yourself or for the person you care for?



Difficulties talking to health professionals

TRUST is essential for young carers and came up throughout the session. Many of the group had previous experiences which can make it difficult to trust health and social care staff:

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“I get a bit worried because the doctors always let my mum and nan down” – a young carer whose nan passed away felt like the doctors could have done more to help her

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“When they said they’d do an operation or something, they’d do it 3 or 4 days later, but when they needed it then they wouldn’t do it then” – feeling like doctors don’t stick to their word or provide care when it’s needed can damage trust

Word of mouth –

“hearing that a service has been recommended by a friend makes me more likely to go to them”

Explaining what the treatment will be beforehand–

“When I had my appendix out [they said] we're going to put you under anaesthetic and ... we're going to do this big 'fancy word' procedure. I was like, what does that mean? I know what anaesthetic means [but not] the procedure”

What helps to BUILD trust?

Staff who listen to young carers –

“someone who takes what I'm saying into consideration”

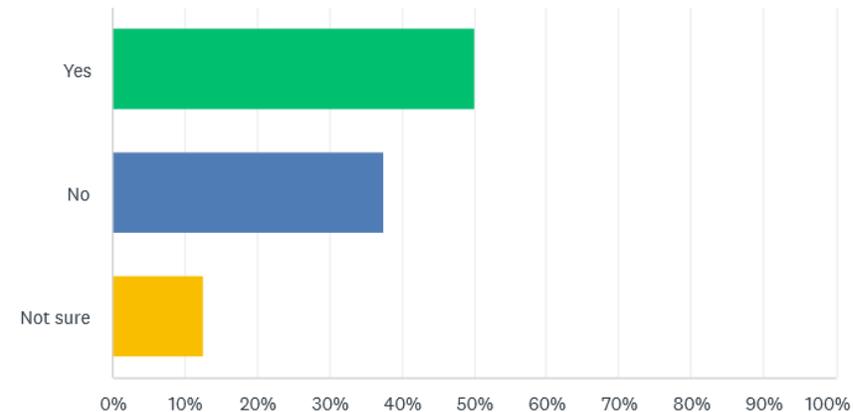
Speaking more slowly and softly – “makes me feel more comfortable”

Using language that young people will understand without being patronising – not in “doctor voice”

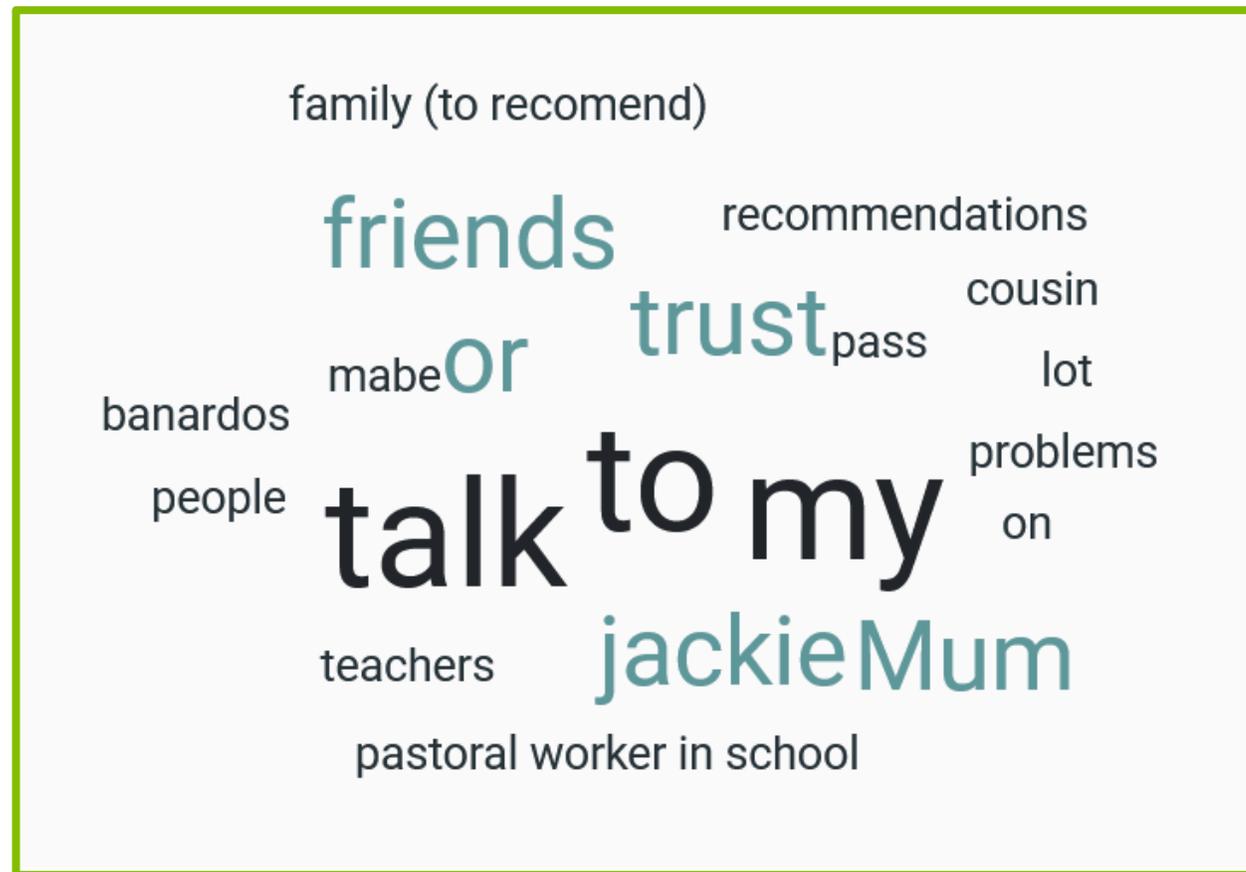
Sharing your views and experiences

When asked in the survey before the session, half of the young carers said they **did** know who to speak to if they wanted to share their experiences of health and social care.

Do you feel like you know who to speak to about your experiences or views of health care?



Who would you speak to about your experiences of health and social care?



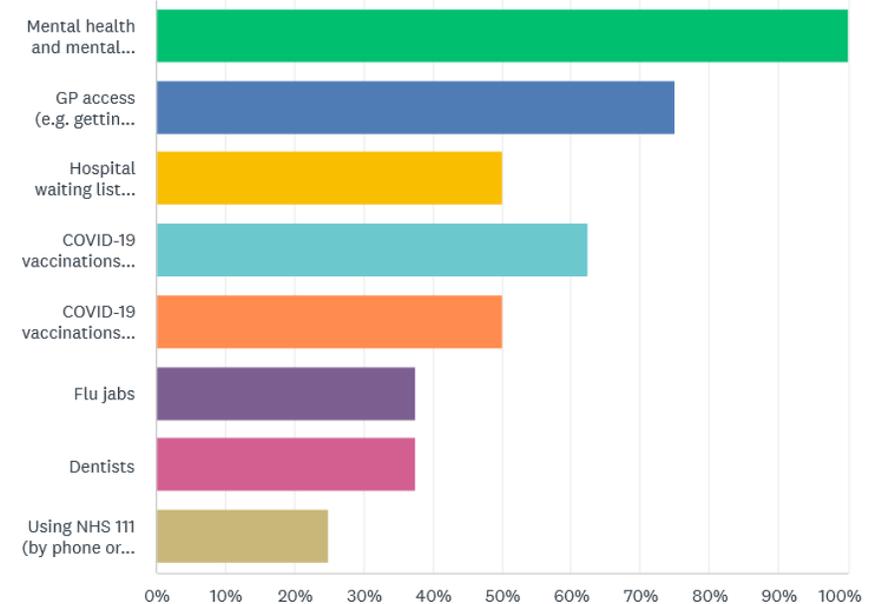
What is important to young carers?

In order to plan the session around the interests of the young carers, Healthwatch Wirral asked which topics were **interesting** or **important** to them.

For this session we focused on the top three topics chosen by young carers who answered the survey:

1. **Mental health**
2. **COVID-19 vaccinations for young people**
3. **GP access**

Which of the following health topics are interesting or important to you?
(choose as many as you like!)



Mental health

All young carers who answered the survey chose mental health as an interesting or important topic.

During the session the group identified a number of gaps and issues with the current mental health care system, including:

Needing time to build trust

Lack of awareness around what might be a 'safe space' to discuss mental health

Waiting lists

Need for whole family support

Lack of support during COVID-19 pandemic



Mental health – trust and time limits

TRUST came up again when discussing mental health:

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As a person who comes from a family with mental health problems, including myself, I find it really helpful if there's someone you can trust. But it's also really unhelpful if you just get put into counselling with someone that you don't really know, at all. And then it's just like, you're almost expected to talk to them, even if you don't want to. And then obviously, you don't talk to them. And they say you're fine when you're obviously not.

- Mainstream mental health care often involves a counsellor being assigned to you and there is often a time limit on how many sessions you get
 - Young carers felt this was unhelpful as it doesn't allow time to build a trusting therapeutic relationship which would allow young people to feel safe opening up about their mental health
- One person was offered a six week 'regime' which they found difficult

Mental health – waiting lists

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I think that there needs to be a bit more mental health support on the Wirral, and it needs to be a bit more quicker

- Healthwatch Wirral is aware of many third sector groups offering mental health support (in addition to NHS mental health care), but the young carers raised two key points:
 - The need is still greater than the amount of support available
 - Many people aren't aware of what support is available or how to access it
- Waiting times are one of the most frequent concerns we hear at Healthwatch Wirral across health and social care services, including mental health care
 - Young carers see waiting times as a barrier to mental health both for themselves and for the family members they support

Mental health – lack of support

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My mum has been with the mental health team for two years, but then since COVID started, they haven't spoke to us since then, like a year and a half, they haven't spoke to her or anything

- Even when someone is supposed to be receiving support (e.g. community mental health) it's not always there – waiting lists aren't the only issue
- Staff have been stretched during COVID as the need for mental health support has only increased – people can fall through the gaps

Mental health – whole family support

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I was like, doing bereavement [counselling] after my nan died. And then I was doing stuff with Jackie as well... And then my mum is doing really well but she needs more support and it's not there, because the doctors don't really think of it as an issue, but it is, and they don't try and sort it

- There is a need for a whole family approach to mental health, especially after major life events such as bereavement which affect everyone in the family
- Parity of esteem – mental health is sometimes still not taken as seriously as physical health

Mental health – medication

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I know someone who has been on antidepressants or something like that. And like, the doctor's just given them antidepressants without kind of looking further into the problem of what's causing this. So I feel like they should like, talk with them, ask them "what's going on in your life, what's troubling you and making you have these feelings?" instead of just giving them medication to help it

- Young carers see the need for exploring the underlying causes of mental health difficulties rather than just treating the symptoms
- Offering medication without counselling and therapeutic support alongside can be exacerbated by long waiting lists – doctors can refer people for mental health support but medication can be prescribed immediately

Mental health – safe spaces

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In our school in form time, we did a survey of like, our mental health. But I really did not like that. Because one it's confidential... but everyone next you could see, and it was just really annoying... And I was trying to answer honestly... And it's really bugged me today as well, because only 10 people out the whole entire year is getting this therapy thing. And it's like, I don't think that's right, I think it should be open. If you want it, come get it, don't like just pick some people off a random survey.

- Need for safe spaces to talk about mental health – even a survey can be very personal and hard to be honest in a room full of peers
- Lack of safe space – some people who really need help won't get it because they can't be honest about how they're feeling
- 'Rationing' of therapy – not an open offer, just those assessed by survey – not necessarily available if you ask for it

What helps your mental health?

Spending time with family, talking, and creative activities like cooking and music were all identified as things that can support young people's mental health. Some answers also pointed to a need for distraction – "constant work" and "being busy".



GP access – what does 'access' mean?

GP access was the second most popular answer after mental health.

We started by discussing what access means and how it covers lots of different areas:

E-consult

Booking an appointment

Physically getting to an appointment

Additional needs e.g. translation, learning difficulties

The group discussed their own barriers to GP access, including:

Difficulties changing GP due to COVID-19

Lack of trust in GP due to past experiences

Not enough face-to-face appointments



GP access – quality of care

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I live in a place which is practically near everything... Quite good for where everything is, but we're not great in the quality of what everything is. So our GP isn't great. And we've wanted to move for a while and mum has been able to but the rest of my family hasn't, which is really annoying, because there's a GP about 20 minutes away walking which isn't bad... but there's just no available spaces at all. Everything's gone up because of COVID. Which makes sense, obviously. But I just feel like how many spaces they're letting in can really affect people and also the quality of GPs.

- Physical access to a GP isn't everything – the quality needs to be there too!
- Moving GP is especially hard right now because of COVID
- Healthwatch Wirral asked what “our GP isn't great” meant for this young carer:
 - Not getting medication on time
 - Not sticking to what they say e.g. medication will be ready on Monday
 - History of misdiagnosis:
 - “they do the bare minimum”

GP access – lack of trust

6 We're with the GP. And my mum, when she tried to apply for one she had to wait two whole days, but with the conditions that my mum's got she could have ended up in hospital by the time they replied. And when my mom like rings them now they say they'll call back and reply, but they don't respond or call back. So they're not very trustworthy, reliable.

- Waiting times can have an even greater impact for people with disabilities and underlying health conditions
- Lack of trust is huge – being let down repeatedly has a knock-on impact

Healthwatch Wirral asked: Does your mum's experience make it harder for you to reach out for help?

"Yes, to be honest, because of what's happened in the past... Say for example, a dentist did an operation wrong, you wouldn't trust them."

GP access – face-to-face appointments

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“I think there needs to be like, more face to face appointments. Because like, my mom works with a lot of Deaf people. And, like, they can't obviously hear, and they'll need a sign language interpreter. So like, when it's like phone call appointments, they can't do that. Because they can't, like hear or stuff like that.”

→ Not everyone has the same needs – different forms of access are needed, not 'one size fits all'

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“Another thing about accessibility is because of COVID they're not doing as many face to face conferences... my mom had this problem with her feet a couple of months back and it's been going on for nearly a year. And because they couldn't see it... she just got rejected so many times and now she's getting a small operation on her feet”

→ Phone/video appointments can't replace face-to-face appointments
→ Lack of preventative care or primary treatment can lead to bigger problems down the road

COVID-19 vaccines for young people

The final topic as chosen by the young carers who answered the survey was the COVID-19 vaccination programme for young people.

Due to the ages of the young carers in the group, not everyone was eligible for the vaccine yet:

The young carers who were 12 or older had had their COVID-19 vaccination

The young carers who were under 12 wanted to get it



Why get the vaccine?

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"So I really want the vaccine, because... I kinda guess I want life to go back to normal. Like, because the vaccine isn't going to stop it, but it's going to help prevent it, I guess." (under 12) -
To help life go back to normal

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"I'm turning 12 [soon], like, I want the vaccination... my sister, she said that she should like the vaccine, but she's, but she's not able to because of her age... And she's kind of worried of COVID as well. And she's had it before, so she knows what it's like... And no-one else had it [COVID] in the family, but just my sister, and she said she doesn't want that to happen so she'd like the vaccination to be less chance – to stop that from happening"

To protect others as well as myself

Someone I know has had COVID-19 – I don't want it to happen to me!

To reduce anxiety around catching COVID-19

COVID-19 vaccine - misinformation

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I personally dislike the idea of the propaganda that is based around COVID vaccines, the whole microchip idea... I understand a lot of people don't want it, a lot of people don't trust it. And they're entitled to their opinion. Just don't make me not want it because I wanted it but when I got it, I felt a bit nervous because of all the things people have been saying. And I just don't think that is fair. Because now that I've got it I feel much safer. Because I can go into places and I don't have to like - I obviously have to wear a mask but... I can go to places now. I mean, it hurt like hell, but it was worth it

- Misinformation has an impact even on young people who want the vaccine – can cause anxiety, not knowing what is true
- Young carers want to be able to make up their own minds and have accurate information
- Having the vaccine helps young people feel safer and able to have more 'normal' lives

COVID-19 vaccine - family

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"I got my COVID vaccine a couple weeks ago, and like, I did feel much safer with it, and... my dad doesn't want to get it. And I understand, that because he was on some medication a few years ago. And he didn't want to, like risk his health with getting the vaccine again. And I completely understand that. But he was trying to, like, encourage me not to get it. I understand, like, if you don't want to get it, you don't want to get it like, you can tell me that. But if I want to get it don't try and stop me... [don't] try and take away my health"

- Young carer decided to get the vaccine even though her dad hasn't had it and was encouraging her not to get it
- Vaccine hesitancy can vary even among families, and young people aren't necessarily going to follow what their parents say

COVID-19 vaccination – how to combat misinformation

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There was an assembly on it in school. And I learnt something from the assembly because it was the science department saying how the vaccine was actually developed. It was only quicker because they did it [vaccine trials] with a lot more patients. And I didn't know that – I thought it was rushed, but it wasn't. And there's a lot of things that I didn't know. Because then – not only the news, but Instagram, Tik Tok. They've all been sharing things that aren't true.

- Impact of social media – it can be hard to know what's true and what's not
- It IS helpful to actually debunk/address the COVID myths
- Important to come from a trusted source e.g. school science department
- **What does this mean for vaccine comms targeted at young people? GPs etc may not always be a trusted source (especially for young carers) due to their experiences – who would they trust to tell the truth?**

Survey – additional comments

At the end of the survey Healthwatch Wirral made room for young carers to share any additional experiences with health and social care. All of the responses we received focused on access to health care:

- “Sometimes it is hard for me and my family to get the help we need and we have to try and call early in the morning... but it’s a busy time and we can’t get through”
- “Having no transport to get to appointments and not being able to get there because of the health issues”
- “It upsets me over not being able to get my mum to the appointments she needs due to COVID”
- “Disabled people commonly have to wait for years for things they should be getting immediately”



#Spare5

Healthwatch Wirral finished the session by explaining the #Spare5 concept – taking 5 minutes to help someone else, whether it's practical support, signposting or just listening. Some examples of how people can #Spare5 include:

- Taking your neighbour's bins out
- Mentioning Barnardo's to a friend at school if they might be acting as a young carer
- Signposting to Healthwatch Wirral if someone you know wants to share their experiences of health or social care
- Using Wirral InfoBank to find support services
- An example from the session – one young carer (and #Spare5 Ambassador) shared their own knowledge of an app that might be useful for another young carer!



What next?

This is the second session Healthwatch Wirral have run with young carers. We are very grateful to Barnardo's for circulating the survey and session details, and to Jackie Finn in particular for attending the group to support Healthwatch Wirral in creating a safe space for young carers to share their views.

We would also like to thank all of the young carers who gave up their free time to attend the session. Young carers have a wealth of knowledge around health and care services and we are keen to continue working with them to ensure their voices can be heard by services and commissioners.

Next steps: Healthwatch Wirral hope to hold another session in the coming months, possibly focusing on hospital experiences.

This report will be published on the Healthwatch Wirral website, shared with relevant commissioners and stakeholders, and specific feedback from young carers will be raised at meetings around mental health, GP access and COVID-19 vaccination.

Further reading

- Feb 2022, Office for National Statistics – [COVID-19 Schools Infection Survey, England: attitudes to vaccines and preventative measures](#)
- Feb 2022, Children’s Commissioner – [Briefing on Children’s Mental Health Services](#)
- Sep 2021, NHS Digital – [Mental Health of Children and Young People in England 2021](#)
- Sep 2021, Children’s Commissioner – [The Big Answer](#)
- Feb 2021, Barnardo’s – [Supporting the hidden victims of COVID-19: Lessons from the first wave](#)
- Jan 2021, Children’s Commissioner – [The state of children’s mental health services 2019/20](#)
- Aug 2020, Barnardo’s – [Devalued by Forces Beyond Your Control](#)
- 2019, British Journal of General Practice – [Young carers: unknown and underserved](#)



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