

Written evidence submitted BY POhWER

About POhWER

POhWER was established in 1996 by our founders all of whom had disabilities and were fighting social injustice and challenges in their lives. POhWER supports marginalised, vulnerable, and social excluded people through its' charitable work across the UK. This past year POhWER reached 400,000+ people with advocacy, information, and advice.

We look at everyone who needs a helping hand through advocacy to lead independent lives and to uphold their rights. <https://www.pohwer.net/>

POhWER's advocacy experience in NHS Complaints

POhWER is the largest independent advocacy Charity in the UK and has a significant evidence caseload to draw evidence upon to establish and understand trends. Between 2020-2021 POhWER supported a total of 6,789 NHS complaints issues across the UK.

Our POhWER NHS Complaints Advocates support people with an array of free and confidential services:

- Provide information about how to complain including who to complain to
- Explain the complaints process and options at each stage
- Help beneficiaries to write letters
- Help beneficiaries to prepare for complaint meetings and attend with them
- Help beneficiaries to refer a complaint to the Health Service Ombudsman if they are not happy with the response they receive from the NHS service
- Signpost beneficiaries to other organisations which can help them if POhWER can't

The top 5 reasons where our beneficiaries required NHS complaints support from POhWER advocates during 2020-2021 included:

1. Aspects of clinical treatment – hospital and community services
2. Aspects of clinical treatment – GPs and dentists
3. Attitude of staff - hospital and community services
4. Communication / Information to patients - hospital and community services
5. Attitude of staff - GPs and dentists

The largest volume of NHS complaints were raised against Acute & Community settings.

Who the complaint was made against	NHS Complaints Issue Type	Total Issues supported
Acute and Community	All aspects of clinical treatment	5,255
	Attitude of staff	
	Communication / Information (written and oral) to patients	
	Complaint handling	

	Appointments, delay / cancellation (outpatient)	
Primary Care (GPs and Dentists)	All aspects of clinical treatment	1,463
	Attitude of staff	
	Administration / Management	
	Communication / Information (written and oral) to patients	
	Appointments, delays / cancellation (GP / Dentists)	
Safeguarding - NHS Complaints	Raising an Alert to the appropriate authorities where there is a concern about beneficiary safety.	71

Impact the COVID-19 pandemic had on NHS waiting times

Not all of our complaints work in 2020-2021 was related to NHS waiting times or backlogs, 4% of the total NHS complaints cases related specifically to this area of Parliamentary inquiry.

For our work related to POhWER's own beneficiaries, we analysed and reviewed case data before the pandemic and during the pandemic to understand how trends changed and the impact it has had on individuals using NHS complaints advocacy services.

Pre-Pandemic (2018-2020)

To establish a benchmark and foundation for what a pre-pandemic 'typical' case might look like for our beneficiaries we analysed data for NHS backlogs and waiting times between 2018-2020. What we observed was an annual increase of cases related specifically to NHS waiting times and backlogs raised through our NHS complaints advocacy services rising from 153 cases per annum to 251 cases in the year before the pandemic.

Examples of typical complex cases POhWER would have handled in relation to delays or waiting times before the pandemic is illustrated by the following example ("Kavita's Story") where the NHS were delaying treatment and not adequately taking into account someone's specific communication needs or making an effort to adapt to her disability and reasonable adjustments:

Kavita is deaf and blind and suffers from severe epilepsy which means she is often taken to hospital by ambulance. On virtually every admission Kavita said she was often treated with rudeness and misunderstanding. No efforts were made to explain things or regularly observe or support her. She was delayed in receiving medical treatment and kept waiting on multiple occasions without explanation. The NHS staff perceived that it was not possible to communicate with Kavita.

Kavita asked POhWER to help her raise her concerns with the hospital. When a meeting was requested by her advocate the response was 'how can she have a meeting if she is deaf and blind?'

Kavita's advocate helped her to prepare a letter of complaint which specified her communication needs. The first response from the hospital completely ignored Kavita's request. When a meeting was arranged the hospital would not pay for an interpreter until her advocate quoted equality legislation.

With the support of her advocate, and after a nine month complaint process, the hospital worked with Kavita to develop an About Me booklet which she now carries at all times. A copy is also kept in A&E for staff to refer to.

During the Pandemic (2020-2021)

Following first lockdown, we observe that some themes persist and continue from the pre-pandemic timeframe and some new COVID-19 specific trends arise which include but not limited to the following challenges for our beneficiaries:

- Different perspectives on what is considered urgent and critical
- A lack of consideration for people with multiple needs
- Poor understanding of the impact the delays have had on people's dignity, livelihoods and or ability to operate as equal people in our society
- Information not being made available in formats suitable for people living with learning disabilities or sensory disabilities
- A disproportionate focus on COVID-19 treatment and capacity and not other life threatening medical treatments

With the NHS operating at maximum capacity this led to a sharp decline in routine NHS activity with more people waiting for longer. POhWER managed a total of 297 cases related specifically to NHS waiting times over the last 18 months 2020-2021.

An example of where life-saving treatment was delayed is highlighted in "Mabel's story:

Mabel is seventy three years old and asked for support to make a complaint against her GP Practice after her cancer treatment was delayed.

Mabel had received a cancer diagnosis and was waiting to be referred for treatment. She should have been triaged within 2 weeks but Mabel had post-menopausal bleeding so the GP delayed the referral so that she could have some tests. Mabel had to wait 13 weeks before she was referred for her cancer treatment. In this time, she saw three doctors and two nurses but no one highlighted the urgency of her situation.

Mabel wrote a letter of complaint and the GP Practice responded with an apology. Mabel noticed a number of inconsistencies which she was unhappy with in their response.

Mabel contacted POhWER and was allocated an Advocate – Lian. Lian helped Mabel to arrange a meeting with the practice manager and then accompanied Mabel to the meeting. Mabel was grateful to have the opportunity to speak to them face to face.

Following the meeting, Mabel and Lian discussed details of the case and agreed next actions. Mabel requested audio recordings of the meeting she had with the practice manager. Lian and Mabel agreed, once Mabel had received the recording and had time to listen to the contents, that Lian should send an email to the GP Practice to request a final response letter. Lian liaised with the Practice Manager to aid smooth communication between Mabel and the Practice.

Lian discussed the option of the Parliamentary and Health Service Ombudsman (PHSO) should Mabel wish to take the complaint further. Lian answered Mabel's questions about these options and gave her a printout of the PHSO information pack.

Mabel received a final response letter from the GP Practice. She felt that her issues had been addressed in the final response letter. She felt that her voice has been heard and no longer wanted to pursue her complaint to PHSO level. She hopes that her complaint has raised awareness of catching and treating cancer early and that referrals should be made in a timely manner so that future patients don't experience the delays and anxiety that she did.

Lian's support enabled Mabel to protect her right to freedom of expression (Human Rights Act 1998) by helping her to raise her complaint and be heard by the GP Practice. By raising her complaint Mabel was able to protect her right to life (Human Rights Act 1998) by challenging the GP Practice when they made the decision to delay treatment which she felt affected her life expectancy.

Looking at POhWER's cases which start at the first lockdown there are several other beneficiary examples which support these new worrying trends and impact NHS delays had on our beneficiaries:

- *Mary's story – a night worker who on several occasions had appointments cancelled on short notice with NHS to treat a painful ovarian cyst.*
- *John's story – a schizophrenic man who was alone and without access to medications or mental health crisis treatment during pandemic.*
- *Simon's story – a POhWER beneficiary who had to wait 9 weeks for a wheelchair in 2020 and felt the NHS had left him without 'his legs' or adequate care support.*
- *Izram's story – a refugee who was a victim of torture in his former country who had surgery to correct his disfigurement, scars and wounds cancelled on multiple occasions by the NHS.*
- *Anna's story – who lived with Autism and ADHD and did not receive a referral to support audiology appointment in reasonable time and had to wait 9 months for a hearing aid to be approved.*
- *Zara's Story - it was agreed that the hospital would arrange for epileptic equipment to arrive at her home. Unfortunately, the equipment never arrived.*
- *Jasmine's Story - An elderly patient with visual impairment was given the wrong medicine for her symptoms by her G.P practice. The G.P practice did not rectify this issue for two weeks leaving her in pain during the pandemic.*

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