

# Parkinson's UK Swindon & District Survey Report

## Introduction and methodology

Late in 2019 we invited bids from non-profit organisations in Swindon for a small amount of funding to undertake a survey with their contacts or members. These were likely to be people from whom we were otherwise less likely to hear.

Five organisations<sup>1</sup> were selected by our Advisory Group and a standard survey was developed with the groups' involvement. It was adjusted slightly for each to acknowledge the specific differences of organisations' remits. Four were asked to survey up to 100 participants between April and June 2020. One small activity group undertook to survey its 25 members.

Covid-19 intervened and, as a result, the surveys in this report were all completed online by people involved with [Parkinson's UK Swindon and District](#). They therefore exclude any participants without online access.

## Key findings

- Concern at the length of time people have to wait to get a GP appointment and/or see the clinician of their choice.
- The need for more communication about and support to register for online access to primary care services, appointments and prescription renewal.
- Frustration at the inability to book, say, three months ahead for a regular blood test or jab.
- Concern about access to carer support and respite and for the future of the Hop Skip & Jump facility.
- Concern about the post Covid-19 backlog of referrals and appointments.
- Evidence of limited knowledge of Swindon Local Offer and information about services available

## Who participated?

Data was collected between 20 March and 11 May 2020 from 104 people. Not everyone answered every question.

- 69 people were supported by a family member or carer to complete the survey online.
- 95 people were registered with 20 different GP practices in Swindon (out of a potential 24);
- 6 were with Wiltshire practices, 2 with Gloucestershire and one with Oxfordshire.

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<sup>1</sup> The organisations were Parkinson's UK Swindon & District, Swindon & Gloucestershire Mind, Harbour Project, Swindon SEND Families Voice and Swindon Interactive Arts Service (SWIAS).

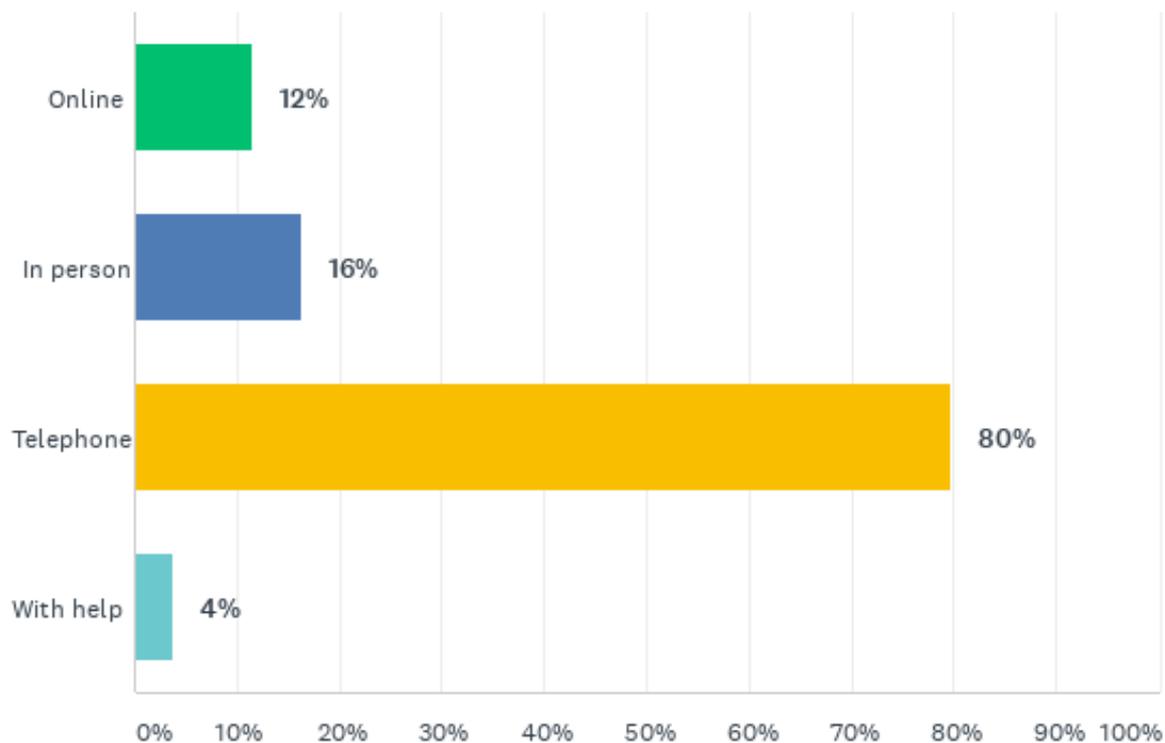
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## What did we hear?

We asked how people made appointments at their GP surgery and how easy or difficult they found doing so.

- 38 said it was easy,
- 44 said neither easy nor difficult.
- 22 (21%) found it difficult.

83 made their appointments by phone; 17 in person and 12 online (some people use more than one method) and 18 people had help to do so. Online appointments were suspended during Covid-19 but in due course will need to be promoted again.



There were many comments about the time it took to get through on the phone, the availability of appointments and the wait to get one, particularly if people want to see the same doctor each time.

*“Very few appointments available, I was even told to ring back in two weeks as they had no appointments available. The normal waiting time for an appointment is six weeks.”*

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*“Left on phone for ages....that man repeating same thing over and over again; this stops receptionist answering promptly. Then you may have to go to Abbeymeads Surgery or god knows where. I have to get a taxi as I can't drive.”*

*“Can be up to ten days to get an appointment. Staff not fully trained. Would not let me have an appointment because they could not see an x-ray, despite me telling them that doctor had fuller access through Medway (electronic patient recording system). Told they had to get GWH to send x-rays; on return (reception said) same again; on third return different ladies who agreed with me doctor could see x-ray on system”.*

Conversely one person said:

*“Kingswood surgery are brilliant and deal with most queries on the phone immediately or with a quick call back” and another said “My surgery treat me as a priority patient due to my Parkinson's.”*

**Many had had experience of using various health services during the preceding twelve months.**

- 85 had been to Great Western Hospital,
- 65 to a dentist;
- 47 had used the Clinical Commissioning Group (CCG) [prescription ordering direct service \(POD\)](#);
- 23 had had support from community health services (including podiatry and continence);
- 5 had been in touch with mental health services.

**Experience was varied.**

*“Community Health Services not that easy to access and continuity leaves a lot to be desired. Two recent stays in hospital with Parkinson's-related problems shows very little knowledge or understanding” and “Online service for prescription very easy to use; the problem arises on collection - it is never ready despite allowing days after the notified availability date. Hospital visits always held to appointment time. Dentist no problems”.*

**Some people completed the survey as Covid-19 began to have greater impact.**

At various times during the survey, access to the POD service by phone was frustrating. The POD service introduced an email request arrangement to give additional capacity - and, from comments in the survey, its retention post-Covid would be of benefit.

*“POD was good but a long telephone queue due to Covid. Hospital stay was not positive, we were not kept informed but again, this was also due to Covid”.*

*“The pod is useless for some people who find phone calls difficult”.*

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*“The service at the Betjeman clinic is second to none” and “I receive excellent service for my Parkinson's condition”. “Speech Therapy, Physio and Dentist very good. POD - extremely difficult to contact them - always a long wait. Hospital needs more consultants and nurses”.*

*“I have had only good experiences. POD is very efficient. Recently had dentures, no problems. Services have been fantastic.”*

*“During my father's hospital stay we found it very difficult to get information and updates on his condition. We were not allowed to visit and he cannot use a phone so it was difficult given the current situation with Covid”*

*“We weren't given the correct information for using Script-easy sheaths. We needed barrier wipes but this wasn't explained to us; consequently had a year or two of very bad experience with leakages etc.”*

*“Hospital in September 2019 promised I would get a letter after leaving. None sent. I had to go again in December. Left letter in office that Consultant operates from. He sent a letter to GP two days later and I got one also. (It said) they would be in contact shortly. (It's now) 23 March 2020. Nothing so far...”*

## Fewer people completing the survey receive social care support than health services.

- 10 had help at home from five different agencies;
- 5 had been attending a day centre which would have been suspended during Covid;
- 7 people had been attending the respite sessions at the Swindon [Hop Skip & Jump](#) centre in Shaw which were supported by Parkinson's Swindon & District. Hop Skip & Jump appointed administrators in March and announced their closure in June 2020.

All but two comments were positive:

*“Lovely carers but a lot of different ones and timings are very varied. This makes it stressful as I have to take meds before I'm able to get up. So I have to wake up early just in case. Sometimes if I've not slept well I could have stayed asleep longer”. And “Long wait for Adult Social Care for equipment.”*

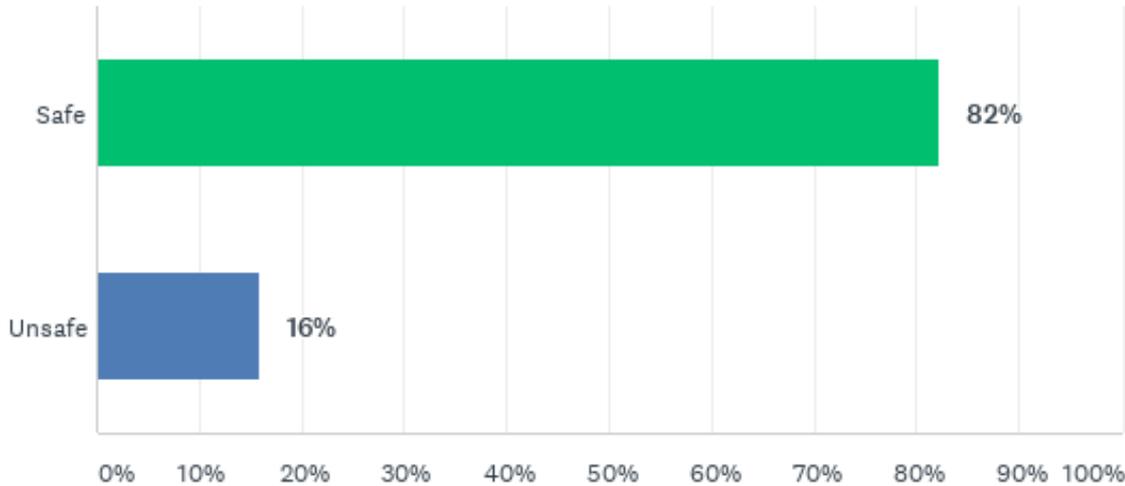
## We asked people how safe they felt in the local community.

Because our surveys are being carried out by five different agencies with participants from different communities of interest, we expected considerable variation in both interpretation of the question and response to it.

All but 16 of these respondents felt safe. Several people referred to instability because of their Parkinson's and to the condition of footpaths and roads; several to the consideration given to them by other people aware of their condition, though one person said

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*“Everybody in a rush and some don't take into consideration that we are slow”.*



### Covid intervened again and one said:

*“This applies to the present climate as a person with health problems. Prior to the virus I would consider the situation safe”*

### Swindon Borough Council and Healthwatch have recently been trying to gauge the extent to which people understand the term “safeguarding”.

Each of our surveys include the question and there appears to be broad understanding from Parkinson's UK members - and some very detailed. Most people answering the question would have contacted a local agency or professional they were in touch with if they felt someone was at risk. There was little if any specific knowledge of a [single contact point to alert](#).

### What could be better?

Whilst a few responses said services were satisfactory (in one case “perfect”) people have views about the improvements that could be made to health and care services they use.

Comments were primarily about

- speed of response to telephone calls,
- shorter waiting times,
- more support for family carers,
- more coordination between services and
- more funding

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*“We don't use social care services at the moment. GP practice is excellent. We use chiropody privately. Incontinence issues have been sorted a few years ago and we get supplies regularly. Medication comes regularly and promptly. Specialist nurse calls straight back re queries.”*

*“I think the team at the Betjeman centre are well organised but they are stretched and if there were more of them they could do more reaching out to the most difficult cases, housebound, care homes, liaising more closely with primary care. Patients like me who can drive to GWH and walk in from the car park are not the ones most in need. This disease is getting more prevalent (impact of pandemic notwithstanding) and in my opinion is still under-resourced and undertreated.”*

*“Homeline would only help if someone had fallen on the floor which is not good enough when help is needed to get up from a seated position. On one occasion my husband was marooned on a sofa from 8.00 pm until 4.30 pm the following day i.e. 20 hours. Eventually helped by the ambulance service, which took a long time because obviously it was not a priority need. There was a lack of care as neither his First City carers nor Homeline took responsibility to help him. Disgusting treatment for a man of 82 years of age.”*

*“More frequent appointments/reviews available with Parkinson's doctors and more frequent assessments available for carer and Parkinson's sufferer. Maybe an A-Z guide of who to call for what.”*

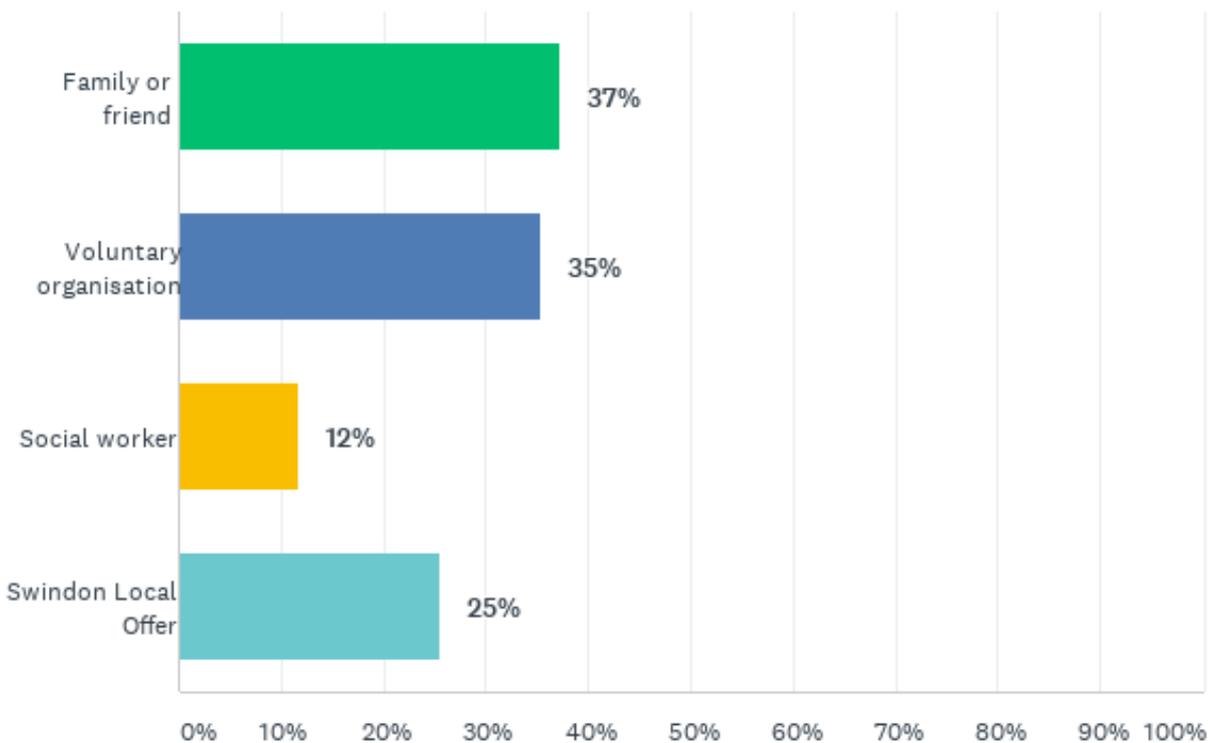


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## Where do people go for information?

We wanted to find out how familiar people are with the available sources of information about services and where they go to find out more.

- 38 would ask family or a friend,
- 36 a voluntary organisation like Parkinson's UK or Swindon Carers Centre,
- 26 were aware of [Swindon Local Offer](#) (one said "Bingo - I didn't know it existed - now I do!"),
- and 12 would ask a social worker or other professional, GP or Parkinson's nurse.



## We asked what one thing would improve people's health and wellbeing.

- Being free of Parkinson's featured several times,
- others referred to better and quicker access to hospital and physiotherapy appointments,
- more physical exercise,
- seeing the same GP each time,
- home improvements making access easier,
- more understanding by others.

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*“A cure but I'd settle for a stabilisation therapy that would stop progression. Seriously the PUK exercise programme is very helpful. For me personally I have enough support and information but I think systematic monitoring and support so no one slips through the net is a good thing.”*

Covid-19 again intervened.

*“I would like a face to face medical review with a doctor re my meds. It can't happen now with this virus.”*

## Who completed the survey?

*People living in SN and GL postcodes completed the survey (not all with SN postcodes live within Swindon Borough) and the numbers reflect that they were self-selected.*

SN15	1
GL7	2
SN7	2
SN1	5
SN2	7
SN4	9
SN25	10
SN5	11
SN6	14
SN3	38

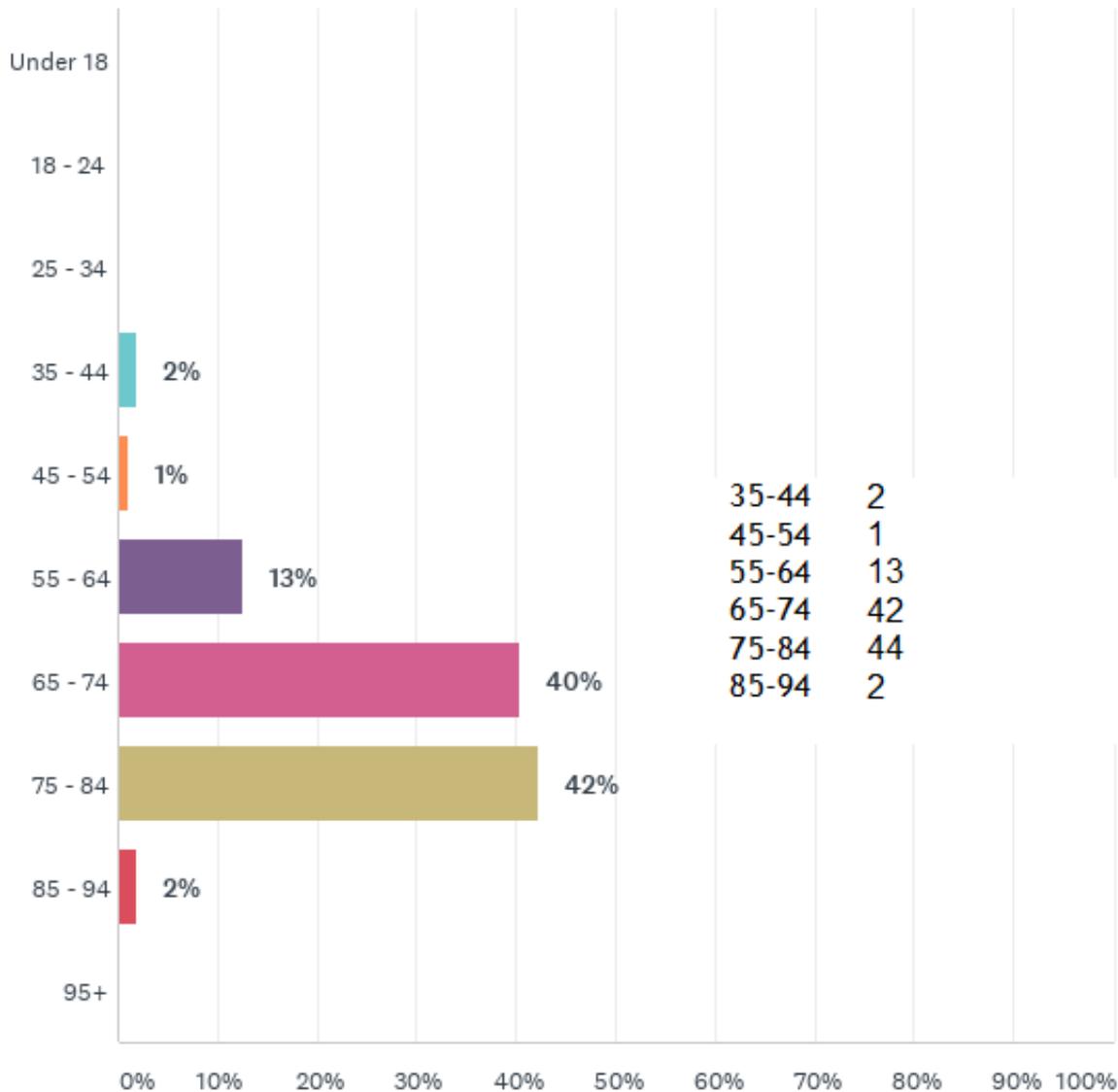
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**Welcome to The Swindon & District Branch of  
Parkinson's UK**

**<http://www.swindonparkinsons.org.uk>**

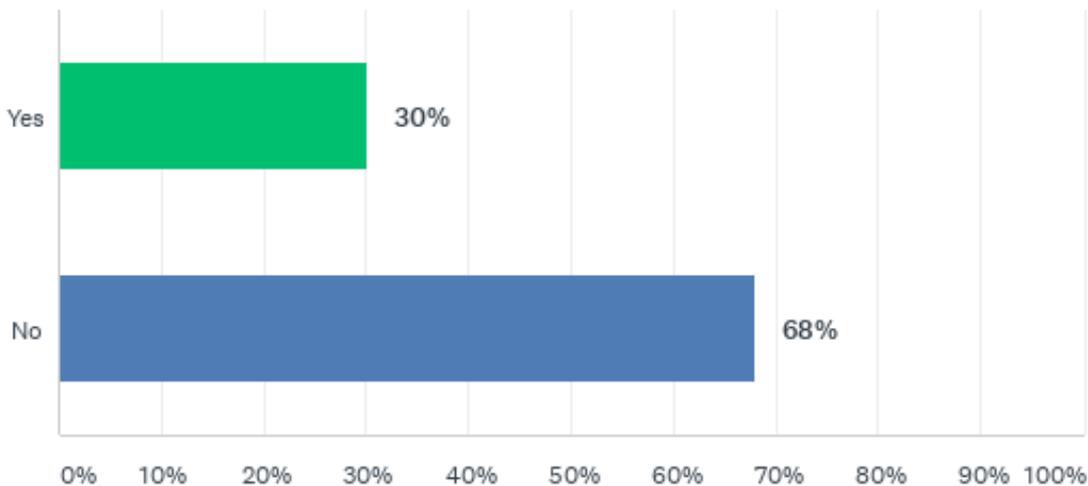
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*Reflecting the membership of the Parkinson's Swindon and District group, most people were aged between 55 and 84. All but three were White/British. Three identified as Irish. 61 were male and 42 female.*



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32 people considered they had disabilities (as well as living with Parkinson's) and 31 said they had a long term physical or mental health condition. These included arthritis and pain, diabetes, asthma, COPD, heart disease, memory problems and dementia, sight and hearing loss, stomas and continence problems.



## Conclusions

- There is and will remain concern at the length of time people have to wait to get a GP appointment and/or see the clinician of their choice.
- There needs to be more communication about and support to register for online access to primary care services, appointments and prescription renewal.
- The email access to Prescription Ordering Direct (POD) should be maintained
- Patients should be enabled to book, say, three months ahead for a routine blood test.
- Respite services which were available at the Hop Skip & Jump facility should be maintained.
- Swindon Local Offer should be widely promoted.

***We would like to thank Parkinson's UK Swindon & District for supporting this piece of work and their members for sharing their views with us.***

