



Covid-19 First Wave Survey & Post First Wave findings in West Berkshire

Feedback & Recommendations

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“I just think the NHS has done a great job over this pandemic in very difficult circumstances.”

INTRODUCTION

Healthwatch is an independent, statutory organisation responsible for ensuring the patient/public voice is heard. It also monitors health and social care services on behalf of patients. There is a local Healthwatch in every area of England.

As the most important part of the Healthwatch role is listening to the views, experiences and thoughts of residents, at this time it is important that we know how the pandemic has affected individuals and families across our region, hence this survey.

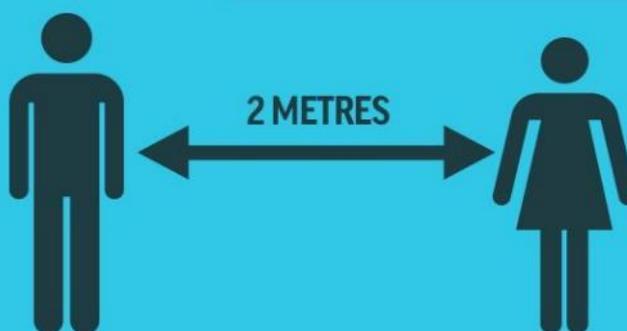
What you have to say about your experiences is important and as committed members of the community we have the authority to make your views heard and campaign for change.

A survey was carried out jointly by Healthwatch Reading, Healthwatch West Berkshire and Healthwatch Wokingham. However, Healthwatch West Berkshire (HWWB) also added a number of additional questions to make the most of the opportunity to engage with our residents. HWWB has also had an ear to the ground throughout the pandemic.

This report covers the additional questions included by HWWB, as well as other information gleaned since the survey closed, as this is more up to date. It provides the views of 301 respondents and those in touch subsequently with HWWB.

Genuine quotes are included to support the text and additional quotes are included within the Appendix.

**YOU NEED TO STAY 2 METRES
APART TO **SAVE LIVES NOW****



EXECUTIVE SUMMARY

The COVID-19 crisis has challenged and affected us all, although in different ways. Our survey and subsequent feedback highlight some of the key issues.

Feedback via online consultations was generally good, with more positive comments than negative ones towards Health services. The survey did not probe social care services in any real depth, an unfortunate omission. Only through good local networking was it possible to capture and feedback social care issues to help improve support to West Berkshire residents.

Telephone and online services generally were thought of positively, although there were some people who were disadvantaged because of lack of hardware and/or their confidence with technology or means to 'connect'. This was made more difficult for some because they were not offered a choice of the how they could contact services. Therefore, it was not known whether they had any difficulties or not.

Getting an appointment 'seems' quicker and easier, although access to technology may be necessary to do so.

Young people have generally been affected less physically, but are suffering socially, mentally, and economically. However, with new variants of COVID-19 this could alter.

It has also become clear that there was a huge anxiety created in the public as everyday services moved online, changed location, were suspended, or just stopped operating. Major issues arose around services such as Phlebotomy, Memory Clinics, Health Visiting, Scans and specifically Dental, which effectively ceased to operate in any meaningful way for many months in the first half of 2020.

Things were made worse by a huge gap in communications around non COVID-19 services. It became clear there were huge holes in pandemic planning for many services and certainly not enough resources in system communications teams locally. Coping with the fast-moving changes in Health/Social Care/Council Services was needed and was quickly arranged with the setting up of the Voluntary Response Hub. Sadly, NHS England disallowing timely local communications, with unnecessary central NHS control, increased the communication vacuum and learning from this is essential going forward.

Another disappointing aspect was the fact that West Berkshire Council, who monitor care homes and Domiciliary Care services, suspended Care Quality Meetings. These meetings monitor Care Homes and Domiciliary Care services. Listening to feedback & challenge from partners would have been helpful. The West Berkshire Integration Board Meetings responsible for discussing joint working between Health & Social Care were also suspended. It would have been helpful for cut-down meetings or reports to have taken place and this missed an opportunity to highlight local Health and Social Care issues that were affected by service changes during the pandemic's first wave. There were certainly issues around true integration and gaps reported by the public that would have been good to share. Often just having the right people in the room solves an issue.

EXECUTIVE SUMMARY (CONT)

Of major concern was the Health & Wellbeing Board (H&WB) deciding not to meet to discuss how the system was working as the pandemic initially spread. It does beg the question if it is not important in the face of a 100-year event what is its role?

The Berkshire West CCG, & specifically Royal Berkshire Hospital, did foster good practice by providing information through weekly meetings with local Healthwatch across Berkshire West initially. We became able to really understand the impact of changes to services and share important feedback from the public. This sharing of information worked both ways and considerably helped us to answer public questions that arose.

It became clear that cancelling key program Boards such as Planned Care, Mental Health & LD and Primary Commissioning was unhelpful, if understandable, with the system pressures of COVID-19. Shortened alternative 'situation report' (sitrep) meetings would have provided an opportunity to offer public/patient feedback to the relevant officers, as well as a vehicle to disseminate out to the public through the Healthwatch daily/weekly 'digest'.

The recommendations of this report have been given a high degree of consideration and it is important that these are received and reflected upon by those with the power to shape local and national Health, Social Care, and general wellbeing policy. We should celebrate all the heart-warming successes & positives from community and professionals alike in combating this deadly pandemic.

However, we cannot have sacrificed so much as a society and then fail to enshrine the learning from those sacrifices. We must capture both the negative and the positive aspects and ensure the public testimony is heard!



(Healthcare Staff who died during the Covid 19 pandemic)

Recommendations Synopsis

Recommendation 1 - Maintaining Covid Volunteering Energy & Broadening the Community Response Hub Membership

Recommendation 2 - Targeting support for both public and front-line staff, including the EDC (Ethnically Diverse Communities), based on need and risk

Recommendation 3 - Improved Timely Integrated Communications

Recommendation 4 - Tangible positive action is taken to show that Carers are truly valued and will be looked after

Recommendation 5 - Mental Health support is faster, more universally offered and less reliant on a 'medicalised' only pathway

Recommendation 6 - Phlebotomy Services be radically transformed

Recommendation 7 - NHS dental services undergo a total national route and branch redesign

Recommendation 8 - Identifying the vulnerable and mitigating embedded inequalities

Recommendation 9 - Staff wellbeing in all Health and Care settings to be risk assessed

Recommendation 10 - Testing needs to be patient centred not system centred

Recommendation 11 - Appropriate Patient Access to Care, avoiding digital exclusion

Recommendation 12 - Barriers to accessing appointments and fear of infection

Recommendation 13 - Amend the Health & Social Care estates accessed by the public, to be fit for purpose during any future pandemic or similar crisis

Recommendation 1 - Maintaining Covid-19 Volunteering Energy & Broadening the Community Response Hub Membership

COVID-19 has brought out the best of our volunteering spirit. The challenge now is to capitalise on this positivity and maintain the engagement. We need to make sure that those who want to help can continue to do so and those who need help get it.

West Berkshire's Community Hub was felt to be a helpful and positive development by those who made contact. However, there were difficulties for some with access and some were given a signpost to another information point when they had expected a referral to a service or immediate help. It is important to always consider, when services are setup digitally, how those who are digitally excluded can have access.

- a) West Berkshire Council (WBC)/Berkshire West Clinical Commissioning Group (BWCCG) should consider building on the local community response hub to create a joint Community/NHS Volunteer 'Reserve'. This could be called upon when there is a need and/or as an emergency response e.g. vaccinations, extreme weather events, major incidents, staff respite, etc
- b) The Health and Wellbeing Board (H&WB) should consider broadening the membership of the Community Hub so that not only can it manage, administrate, and signpost enquiries - but also have the ability to solve some of the problems. For example, it would have been helpful if the CAB, local Healthwatch and key voluntary sector organisations (Foodbank, Furniture Project, Age UK, Fairclose) had been included operationally. Additionally, a greater integration with NHS volunteers service would be helpful and should be requested from NHS England

Action by: H&WB/BWCCG/WBC/NHS England



Recommendation 2 - Targeting support for both public and front-line staff, including the EDC (Ethnically Diverse Communities), based on need and risk

Marginalised groups, particularly the Ethnically Diverse Communities (EDC), those people in deprived areas and older people in care homes, have suffered particularly badly in the pandemic. We must redouble our efforts to stop this re-occurring, enshrine reducing health inequalities into all programs and work towards fairer, more equal, and more inclusive communities.

Currently blunt instruments such as age, level of assets, or a building's normative title i.e. Care Home/Community Hospital are used to determine who is helped and where resources can be used. Leaving out vulnerable residents in places incorporated as 'Supported Living', 'Shared Lives' and 'Homeless Hostels'. It must be asked why government left these establishments off the PPE and infection control assistance programs at the beginning of the pandemic?

This also had an impact on the protection of key frontline staff in Health/Social Care/ Emergency Services/Logistics who needed to be involved with these residents. Better use of population health/risk data based on actual vulnerability (including years of life lost) to drive support used for the wider general population would in the long term reduce health inequalities and increase life expectancy for this cohort, not just around COVID-19.

- a) The H&WB ensures all system partners use up to date Population Risk Assessment Management and data more appropriately to target care resources to where they are needed without exceptions or inconsistencies based on categories/coding, but on need/vulnerability
- b) The H&WB ensures system partners correctly code and record outcomes from the EDC and other communities at the highest risk, benchmarking locally and nationally over the next five years to monitor material improvements

Action by: DHSC (Department of Health and Social Care)/MHCLG (Ministry of Housing Communities & Local Government)/NHS England/ PHE (Public Health England)/BOB ICS (Bucks, Oxon, Berks West Integrated Care System)/ BWCCG/ West Berkshire Public Health/ WBC Adult Social Care

Recommendation 3: Improved Timely Integrated Communications

The messaging coming down from NHS England/Public Health nationally and via the national media has not been consistent with the messaging and activity locally. This has caused confusion and anxiety. Messaging both nationally and locally needs to be consistent, especially in a situation where the message is complex and the situation stressful.

Inconsistent messaging has left many feeling unsure about what they can and cannot do - i.e.: were particular departments closed, should they attend hospital appointments, should they contact the department or should they wait to be contacted. In addition, in some cases there was no communication at all (e.g. Dental services); this led to the rumour-mill being set in motion, which in turn led to the dissemination of incorrect information and unnecessary stress for many.

- a) BOB ICS, BWCCG, WBC, WB Public Health ensure communication teams in both Health, Local Authority, Public Health are properly resourced to guarantee they can communicate *ALL* relevant messaging to the public in a timely, clear way that reduces uncertainty, lowers anxiety, helps clarity of message and speeds up patients accessing treatment appropriately - telephone lines to GPs often blocked because of this!
- b) BOB ICS, BWCCG, WBC, WB Public Health need to ensure accessible or translated communications are available simultaneously to the vulnerable e.g. EDC, the disabled, LD community in line with the Equality Act & NHS Accessibility Standards. So not an *afterthought* or leaving the public relying on Doctors of the World, Sign Health, Mencap etc
- c) WBC, the H&WB write to NHS England to ensure in future locally relevant non-controversial communications can be published with local agreement *quickly*. Additionally, that more sensitive communications are authorised through a swifter process. This would make sure that local information, as it relates to national media information, is always explained fully to West Berkshire residents & they are not kept in the dark
- d) That residents are told if there is no additional or new information in relation to services, treatments, as silence increases anxiety and the spread of misinformation

Action by: Action by: NHS England/Healthwatch England/BWCCG/H&WB/PCNs/WB Public Health/WBC/WBC Adult Social Care

Recommendation 4 - Tangible positive action is taken to show that Carers are truly valued and will be looked after

Support for *Carers* (unpaid) was a significant problem during the pandemic. Many saw their own support or respite disappear altogether. For example, those with a personal budget, or those needing access to treatment and help through assessments pathways all found them largely cancelled or postponed. This was especially problematic for those looking after residents with Dementia or early memory difficulties. Additionally, the rules for Carers around isolation and testing were felt to be confusing. Many felt utterly abandoned as they could not access day centres, help from other family members, support from friends/neighbours, or shielded over an extended period with consequences on their own wellbeing.

It is hoped that with the rolling out of vaccines that such extreme difficulties will be diminished or avoided going forward. However, it is important to monitor the situation closely to make sure that local delivery matches local aspirations, and that the Carer's voice is sought and heard when vital support services are amended or cancelled. Ideally all changes should be done in a co-produced way with Carers & their groups.

- a) H&WB undertake pandemic planning and learning as it relates to Carers (unpaid) and those being looked after. This to include where a service is suspended, so that the contingencies necessary to offer mitigation & support are put in place and actively monitored for effectiveness while the service remains suspended. This should be co-produced with Carer groups & relevant voluntary services, so the consequences of service suspension are fully recognised
- b) Additionally, the H&WB oversees the setup of a help/crisis number with partners for rapid response assistance for Carers, similar to the NHS Rapid Response & Treatment Team, to avoid 'carer crisis'. This could be working in co-ordination with the revised Community Hub, ASC, Community Health Teams
- c) The H&WB launch a new '*Carers Charter*' and a joint WBC, BWCCG, TuVida*, '*Carers Card*'. This card to recognise the carer role and be coded for ALL systems, no matter who is in touch with the carer & the cared for. Application for this card to be by either the carer or cared for, across all services, such as GPs, Hospitals or WBC Social Care, to ensure no Carers are 'lost'. To encourage carer registration the card could offer new, 'meaningful' benefits, e.g., Council tax reduction, discounted prescriptions, eye tests, reduced travel costs & NHS parking

Action by: H&WB/WBC/BWCCG/BHFT/NHS England

*Carers support provider in West Berkshire

Recommendation 5 - Mental Health support is faster, more universally offered and less reliant on a 'medicalised' only pathway

Mental health difficulties have been reported nationally to be a major cause for concern, and this has been highlighted through our survey. It also appears that mental health is declining further in later phases of the pandemic as lockdown returned. The needs of people with new mental health issues and/or those with lower-level mental health difficulties are of particular concern. Difficulties in just accessing services and long-standing capacity problems of MH services and MH support in Primary Care challenge us not to just medicalise all mental health problems or leave patients receiving little or no help until issues become serious.

- a) The H&WB, BWCCG, BHFT, Primary Care Networks (PCNs), Mental Health Action Group (MHAG) with support from the BOB ICS, increase the speed of the rollout of Mental Health specialists/support in primary care settings e.g., PCNs following that mandated nationally & piloted in East Berkshire CCG
- b) BWCCG, WBC, H&WB work with significant partners e.g., Health Education England (HEE) and the Thames Valley Berkshire Local Enterprise Partnership (TVBLEP) to recruit and retrain many of the people whose jobs have disappeared in new roles such as Mental Health (MH) social prescribers who can refer to community groups or refer back to clinicians. For example, people in public facing careers, such as hospitality, retail etc, could be retrained cost effectively (because they already have significant appropriate skills) to provide initial patient facing Mental Health triage support at primary care or alongside ASC Community Mental Health Team
- c) Ensure the voluntary sector has sufficient support, training, funding to help take on lower-level MH issues, or as people recover from more serious MH issues. To be effective it has though, to be easy to find or be referred to e.g., from Community Hub, Parish Councils, VS, family and friends

Action By: H&WB/BWCCG/BHFT/MHAG/Community Hub/HEE/Thames Valley Berkshire LEP/BOB ICS/NHS ENGLAND

“Raised anxiety leading to lack of sleep. Mainly as unable to support family and friends face to face, and not able to access my regular exercise at the Leisure Centre.”

Recommendation 6 - Phlebotomy Services be radically transformed

Phlebotomy (Blood tests) services require attention both locally and nationally. This became an area of great concern for patients during the pandemic when even emergency blood tests were taking three weeks to book. Inequalities arose because some surgeries were still able to undertake emergency blood tests in very quick turnaround, but those referred to bigger centres, such as West Berkshire Community Hospital, had longer waits. Concerningly, Royal Berkshire Hospital (RBH) largely suspended its walk in & phlebotomy services except to inpatients.

It appeared that staffing was an issue as well as infection control, although we are pleased to report that five new staff appointments have now been made locally and services are almost back to normal. Regular blood tests have been vital for many with long term conditions and those recovering - so good information on the likely effects of changes to monitoring of their condition via regular blood tests should be factored into pandemic planning and any planned service transformation.

- a) The H&WB/HEE/NHS England/General Pharmaceutical Council consider supporting additional Phlebotomy/vaccination training courses for those existing key staff to develop additional skills. This would enable a 'bank' of specifically skilled staff set up on which to draw in case of staff shortages or to improve waiting lists
- b) The 'lottery' on availability of blood tests between secondary care provided services and GP provided services needs addressing, so ALL patients have equal timely access. Payment disparities in where services are provided may also be a driver & should be looked at urgently
- c) HEE/NHS England/General Pharmaceutical Council cooperate to develop the training of staff in pharmacies nationally to be able to also offer phlebotomy services. Pharmacies already have experience of vaccinations & using tracked medical courier services for testing, refrigeration facilities on site, etc

Action by H&WB/HEE/NHS England/General Pharmaceutical Council

“Bloods could have been taken at surgery which would have been a lot better and easier to manage than me having to travel to hospital where Covid patients were being cared for.”

Recommendation 7 - NHS Dental services undergo a total national route and branch re-design

There is a need to revisit the complete closure of the *dental* services at the start of the pandemic. There were problems with setting up the emergency hub, difficulties with sourcing PPE for dentists, poor communications and there remains an issue of equality with this service.

It appears that NHS dentistry has been scaled down to such an extent it is almost impossible to access, although by paying privately a service can seemingly be quickly accessed. The pandemic not only highlights these key issues in community dental services, but also the fundamental inequalities of those able to pay for private dental care against those requiring NHS services. For example, people were offered very long waits, which disappeared when there was an ability to pay.

It became apparent during the pandemic that dental services for those without the means to pay for private dentistry simply were inadequate and patients were forgotten and left to wait months for treatment in, sometimes, excruciating pain. Years of under investment in community dental services created huge waiting lists of up to two years excluding thousands from good oral health often leading to other medical complications and decrease in life chances and expectancy.

Services for some of the most vulnerable e.g., new mums, rough sleepers, those with LD disappeared. No exception or extensions were offered, for example, to mums who could not access their 12-month entitlement to free dental care, due to the inability to access any NHS Dental services during the pandemic.

It also appears the public has a completely different idea of how NHS Dentistry works to that of commissioners and that you need to register with an NHS dentist to access any treatment. This confusion and fear of cost leads to a huge proportion of people not accessing dental services of any kind with the resultant poor results for oral health in adults and children. Community Dentistry was already over-stretched pre-pandemic and in need of a complete overhaul with adequate resourcing to close the inequality gap in relation to good oral health.

- a) NHS England considers a total national route and branch redesign of NHS Dental services and creation of a new service *The National Health Dental Service*, rather than the current NHS Dental services as an arm of an unaccountable centralised NHS specialist commissioning team
- b) H&WB requests NHS Dental commissioning for the South East to attend a special meeting to discuss future dentistry/community dentistry services, both in the short and medium term, with patient and voluntary sector involvement

Action by: H&WB/DHSC/NHS England/General Dental Council

“I'm told I could go private by the same ones that tell me they are full. I can't afford it and shouldn't have to pay”

Recommendation 8 - Identifying the vulnerable and mitigating embedded inequalities

Vulnerable people were disadvantaged during phase one of the pandemic. However, the voluntary sector stepped up to the mark magnificently; their kindness and support was very much appreciated.

There were difficulties for these vulnerable groups with ‘vulnerability’ taken too prescriptively e.g., Care Homes only/over 65s. In trying to identify and support vulnerable groups there were/are major gaps in provision and regulatory monitoring is necessary. A person identified as ‘vulnerable’ may not actually be so, but a person not identified as ‘vulnerable’ may indeed be so. Means testing leaves vulnerable, frail and elderly people unable to access help even though they may be asset rich but cash poor - heating or eating! Hostels and supported living are not classified as ‘*care homes*’, so this area was left initially in the hands of only WBC to attempt to offer support to some incredibly vulnerable people.

Some appointments were postponed because of the pandemic and some people avoided services because of fear of infection.

Those whose life expectancies and general health is so much poorer than the general population, such as those in supported living, sheltered accommodation, homeless hostels, shared lives, were excluded from the ‘vulnerable’ group.

The Ethnically Diverse Community has been identified as a vulnerable group nationally but has not been treated in the same manner as other high-risk groups with special emphasis on accessibility to care and information, cultural sensitivities, and reasonable adjustments.

- a) DHSC/WBC and the H&WB introduce a greater flexibility and more holistic approach to assessing individuals and/or groups in offering support or care e.g. ethnically diverse, LD, rough sleepers/socially isolated/new mums/disabled
- b) The Ethnically Diverse Community should be treated in the same manner as other high-risk groups with special emphasis on accessibility to care, translated information, cultural sensitivities, and other reasonable adjustments
- c) Those in supported living, sheltered accommodation, hostels, shared lives should all have been included without thought into the ‘vulnerable grouping’ as their life expectancies and general health is so much poorer than the general population. Population Health Management should assist with this, but many barriers to help are currently in place due to poor ‘categorisation’ and the failure to look at the person/cohorts holistically

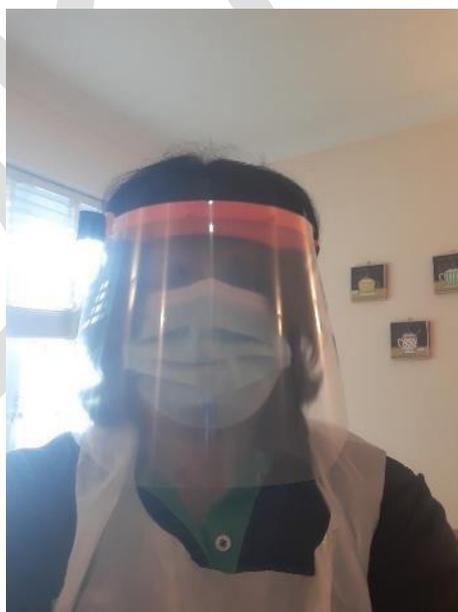
Action by: DHSC/WBC/H&WB

Recommendation 9 - Staff wellbeing in all Health and Care settings to be risked assessed

Front line health and care staff have been affected enormously, in part due to the length of the pandemic. This has had a huge impact on their wellbeing and may well be storing up high numbers of staff who may 'collapse' once the worst of the pandemic is over*. With staff shortages across Health and Social Care it's vital that frontline and key workers are given additional help and are seen to be appreciated to mitigate burnout and increased staff just walking away at the end of the pandemic.

- a) The H&WB oversees an audit of all frontline staff to risk assess if there is a need for additional help, counselling or leave from work. Senior System Organisations urgently consider retraining other staff/ex-staff/volunteers to offer short term respite or stepped down help for patients to give the staff some short-term respite. The Emotional Health Academy model successfully uses part qualified students to fulfil a vital role, and finding a short-term cohort could ensure the NHS/ Social Care does not collapse due to huge increases in staff absence or those deciding to leave the profession altogether due to the sustained pressure of the extended pandemic going on for so long
- b) Staff get an increased holiday period post pandemic for one year e.g. 28 days holiday to 30 as a 'Thank you' & an additional small break

Action by: DHSC/NHS England/WBC/HEE/TVBLEP/H&WB



(*Half of staff who cared for covid patients suffered stress-related illness, national survey reveals, HSJ <https://www.hsj.co.uk/workforce/half-of-staff-who-cared-for-covid-patients-suffered-stress-related-illness-national-survey-reveals/7029666.article>)

Recommendation 10 - Testing needs to be patient centred not system centred

Testing was responsible for many issues highlighted to HWWB that caused problems for the public. The need to get tested prior to an outpatient appointment being one. When an outpatient appointment was booked the hospital could book a test at their own testing site, in the case of RBH in the South Car park, but could not book patients into the local testing facility at the Newbury Show Ground. So, the frail and elderly often with transport issues, were asked to do a forty-mile round trip on public transport or try to access a much-diminished voluntary driver service (due to the age of many of the drivers). In fact, the hospital told people to book it themselves if they wanted to use the showground site, often with dates available for testing coming up after the three-day window requested by the hospital prior to the appointment date. This led to some not going to their outpatient appointments or in many cases the hospital trust having to take the risk and see an untested person.

There was much unease at those being discharged initially without complete knowledge of whether the person was COVID-19 positive or not. This often failed to take into account the frailty of the Carer at home and risk assessments should be done holistically to include the whole family.

- a) All, and any testing systems need to be able to communicate with local NHS systems fully and easily to smooth the patient journey often for the frailest
- b) Testing capacity should be flexible and be able to accommodate patients needing tests for outpatient appointments in good time. Tests should always be undertaken for those being discharged back home or into care homes ensuring that tests are always done & the results known to all who need to know

Action by: DHSC/WBC/HEE/TVBLEP and the H&WB



Recommendation 11 - Appropriate Patient Access to Care, avoiding digital exclusion

Digital Access runs throughout our survey with many references to it. However, digital access means *digital exclusion* for a significant number. Although a fear or lack of confidence will decline as digitally enabled adults grow older, availability/cost of hardware and access to fast broadband service for some and cognitive decline with age of our most vulnerable is likely to remain. This will include some learning-disabled people, some on low incomes and some who will not use IT enough to warrant purchase of hardware. Additionally, there is still some housing, including in rural areas where internet reception is very problematic.

- a) BWCCG and Primary/Secondary Care settings review if/how their systems allow the most appropriate appointment method to be always offered to each patient. Some patients find the use of technology intimidating and they may not be comfortable or able to use it and may be only able to have access face-to-face. It is vital this should include home visits for housebound patients and those shielding or fearful of visiting the practice
- b) Additionally, offering an appointment option with the most appropriate member of the practice rather than only the GP e.g., Physio, Practice Nurse, Pharmacist, Paramedic should be seen as the norm and all 'comms' should reflect this new model nationally - not 'Go & see your GP' for every campaign. Language choices matter, creating demand surges that cannot be reasonably met should always be considered by national bodies
- c) Ensure patient records have the preferred method for contacting the patient recorded for each record across all systems using 'Connected Care' fully and that this is routinely checked/updated at appointments, medication reviews or re-ordering of prescriptions by whatever department, whether health or social care. This should be monitored by the PPG's and local Healthwatch with assistance from key systems organisations

Action by NHS England/Public Health England/BOB ICS/BWCCG PCNs & Acute Trusts



Recommendation 12 - Barriers to accessing appointments and fear of infection

A significant number of people have avoided, and still are avoiding contacting services, as they do not want to take up GP/others' time or they feel that there are other people more in need. This has been highlighted nationally, and there is now a realisation that some diseases are being picked up late with dramatic consequences. People also reported being fearful of catching COVID in hospital or at other health services in person. This fear remains an issue although efforts have been made to communicate the safety contingencies put in place that lower the risk to the public.

In addition, 'do not attend'(DNA) numbers pre-COVID were always a substantial issue for the NHS. It is even more important now to find the root cause of DNAs, as infection control measures during COVID-19 reduces the numbers of appointments for other patients even further.

- a) NHS England commissions local Healthwatch across England to investigate with the public why so many did not seek healthcare for non-COVID-related issues and review other pre-Covid non-attendance issues e.g., "did not attend" (DNA) especially for outpatient appointments. This would help to understand what would improve attendance going forward & reduce wastage of vital healthcare resources
- b) The H&WB oversee GPs/Primary Care Networks (PCNs), Hospitals and Secondary Care settings revisiting their appointment invitation letters/texts to patients and use Patient Participation Groups (PPGs)/the Public/EDCs to feed back on their readability/tone. West Berks Patient Panel/Patient Leaders to discuss, action and feed back to the H&WB their findings within 12 months

Action by: NHS England/Healthwatch England/BWCCG/H&WB/PCNs/WB Public Health/WBC/WBC Adult Social Care



Recommendation 13 - Amend the Health & Social Care estates accessed by the public, to be fit for purpose during any future pandemic or similar crisis

Where surgery or secondary care visits are necessary, attention is needed to provide an appropriate, safe waiting area that does not put people at risk. This will require amending the Health/Social Care Estate to make sure that other harm is not an unexpected consequence of any amendments. Where it is necessary to close a service/practice, it is important to put in place a contingency plan regarding transport to where the service is transferred before changing the service - not waiting for complaints to mount up or a need to *not be met*.

GP Surgeries, Secondary Care, Social Care should *consider* how in the short-term they can put in place socially distanced seating for those needing to rest, as well as a covering from the elements, e.g. pop-up gazebo/part covered walkways etc. WBC Planning team to assist or suspend rules short-term, as is done with emergency services, mobile communication masts or emergency road works.

In the longer-term surgeries/secondary care/social care introduces Pandemic Enabled Design (PED) for all existing and *new* health or social care public facing facilities (e.g. the Royal Berkshire Hospital Redevelopment Project). This to include an audit of the existing estate and include consultation with experts from Infection Control, Public Health, transport, planning, and the PPGs/Parish Councils/local Healthwatch. The latter bodies to report back on progress to the Health and Wellbeing Board.

A similar body to then also look at service changes in a pandemic to ensure that unexpected consequences or access problems are mitigated. For example, the pandemic has shown the need for separate entrance and exits to services, additional car parking and changes to public transport routes.

- a) BOB ICS/BWCCG/PCNs ensure GP Surgeries, Secondary Care, Community Mental Health/Social Care consider how in the short-term they can put in place spaced seating for those who need them, coverings from the elements if outside e.g. covered walkways, 'pop-up' gazebos. WBC Planning Team assist or suspend planning rules short term, as happens with emergency services, telecommunications masts, road works etc
- b) H&WB/BWCCG/BOB ICS/WBC ensure surgeries/secondary care/social care/Community Mental Health buildings introduce Pandemic Enabled Design (PED) to all existing and ANY new building. This to include an audit of the existing estate with consultation from experts from Infection Control, Public Health, transport, planning, Patient Panel Groups (PPGs), Community Groups, Parish/Town Councils/disability groups/local Healthwatch
- c) PPGs, user groups with local Healthwatch report back to the H&WBB/BOB ICS/BWCCG on progress

Action By: NHS England/MHCLG/BOB ICS/H&WB/BWCCG/WBC/PPG

RESPONSES TO RECOMMENDATIONS



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England

Protecting and improving the nation's health

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11 May 2021

Andrew Sharp
Chief Officer Healthwatch West Berkshire
Broadway House
4-8 The Broadway
Northbrook Street
NEWBURY
RG14 1BA

Dear Andrew

Thank you for asking for my comments on the draft Healthwatch report on the first COVID-19 wave. The insights within the report are helpful, and it would be good to share it more widely in the South East.

You have asked me to specifically comment on recommendations 2, 3 and 11.

Recommendation 2

We support both components of this recommendation.

In its current form Public Health England is supporting the development of population health management for Integrated Care Systems. We are providing advice, products, tools and workshops to develop skills in population health management. This is a key component of our work as the public health functions transfer into other organisations.

The expertise in local authority public health departments is critical to bringing a more in depth understanding of the needs of the population and the inequalities that exist.

It is encouraging to see the importance this report places on understanding the needs of the population and reducing inequalities.

Recommendation 3

We agree that timely and clear communications that everyone can understand is important. PHE strives to produce national materials that can be adapted locally. Our communication experts liaise with local partners to ensure they are used to best effect.

We provide press releases and put up spokespeople where this is useful in agreement with the local Directors of Public Health.

The rapidly evolving situation and changing guidance and rules have made it difficult to keep clear and simple messaging. However, this is absolutely what we strive to achieve.

Recommendation 11

The main part of the recommendation is not for Public Health England. I support the ongoing work to ensure communication channels reach as much of the population as possible. Considering and reducing digital exclusion remains a priority.

Other recommendations

Finally, I would like to comment on recommendation 13. I agree that we should use the experience of COVID 19 to consider how we can make our ways of working and estate ready for any subsequent pandemic. I would like to add that we should learn from the impact the current changes have made on a number of other infectious diseases, such as influenza and norovirus, and consider what changes may be valuable over Winters in general.

Your sincerely



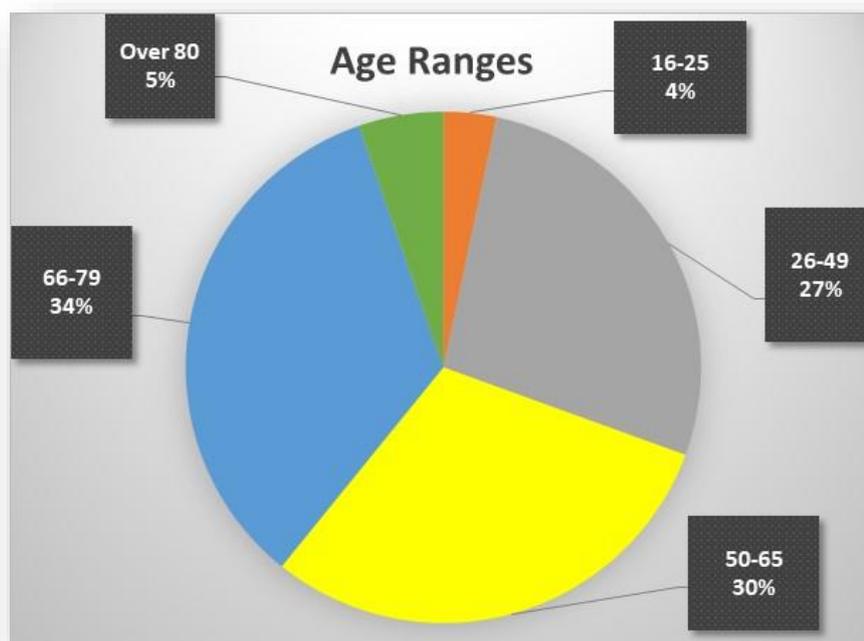
Alison Barnett

Regional Director, Regional Director and
NHS Regional Director of Public Health

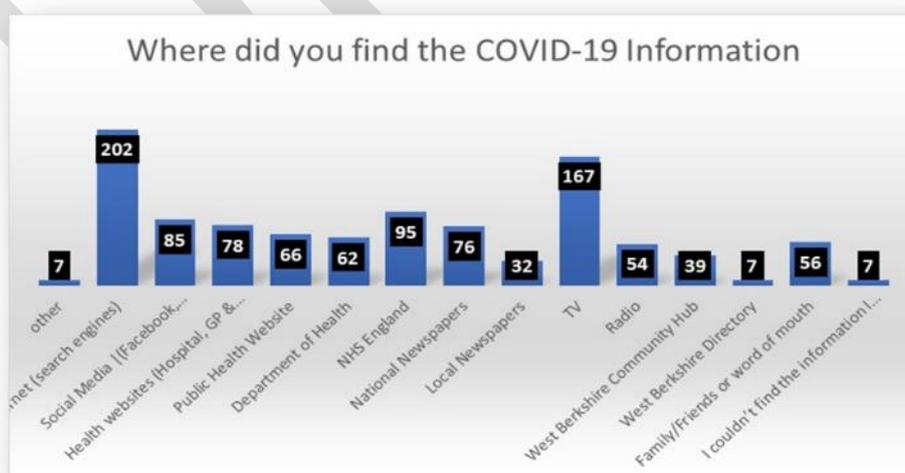
WHO WERE THE RESPONDENTS?

Most respondents were between 26 and 79 with those 16 - 25 or over 80 making up the small remainder. Nearly three quarters were female, and the majority identified as White (91%) with 6% identifying as BAMER and 3% as of mixed/multiple ethnicities.

15% identified as disabled with 84% identifying as not and 1% preferring not to say. The majority of people responded for themselves with a small proportion of their respondents (8%) responding for a relative, partner or close friend. 63% had used NHS/Social care since lockdown on March 23, 37% had not.



FINDING AND UNDERSTANDING INFORMATION



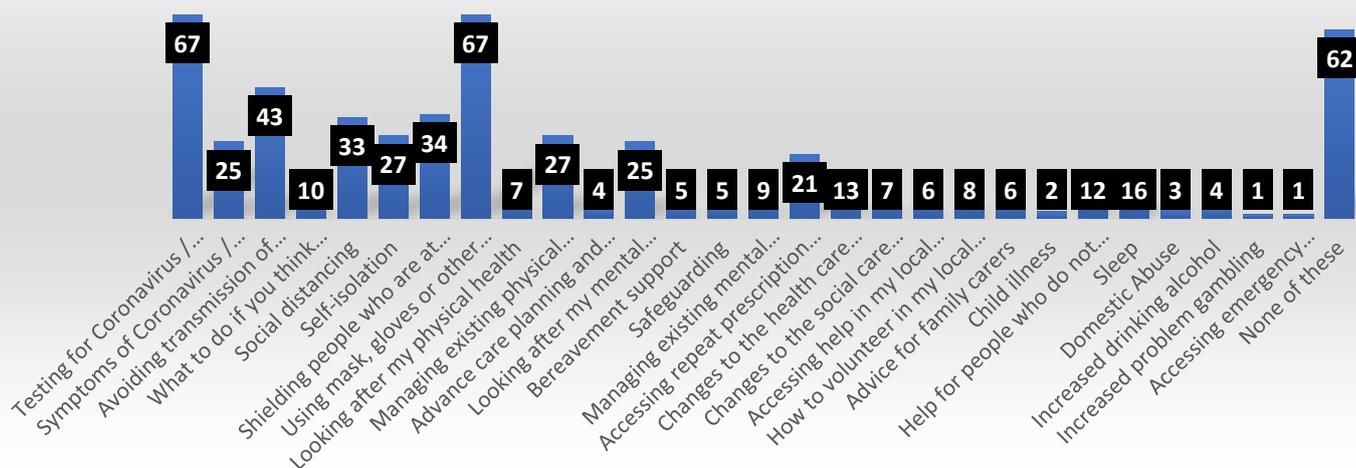
Most people (202) found information through a search engine followed by TV (167). Surprisingly only seven used the West Berks Directory. This may be something that would benefit from further investigation as it may influence where resources are used to greater effect.

The majority of respondents felt well informed and able to understand the information presented. A lesser number felt that keeping up to date with information about safety was easy. However, since the survey there have been reports that information about the ‘rules’ is reported to be confusing particularly regarding the different tiers in different geographical areas.

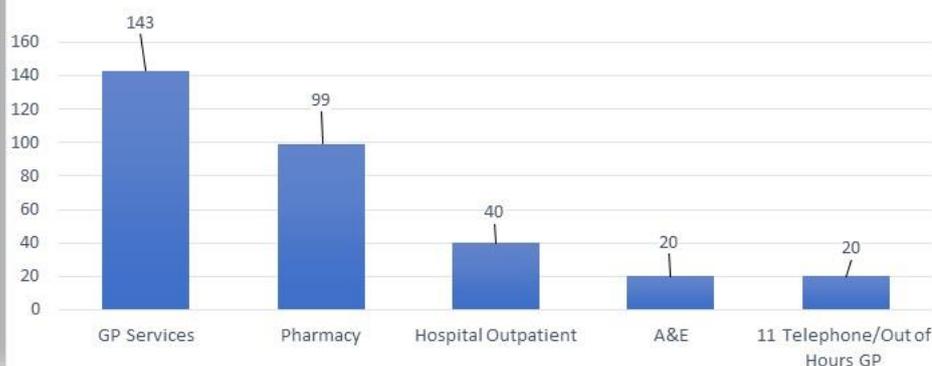
“I am really confused as to what I can and can’t do. I like to go for a coffee but don’t know if I am allowed to sit inside, although I see many people doing this.”

WEST BERKSHIRE COMMUNITY HUB

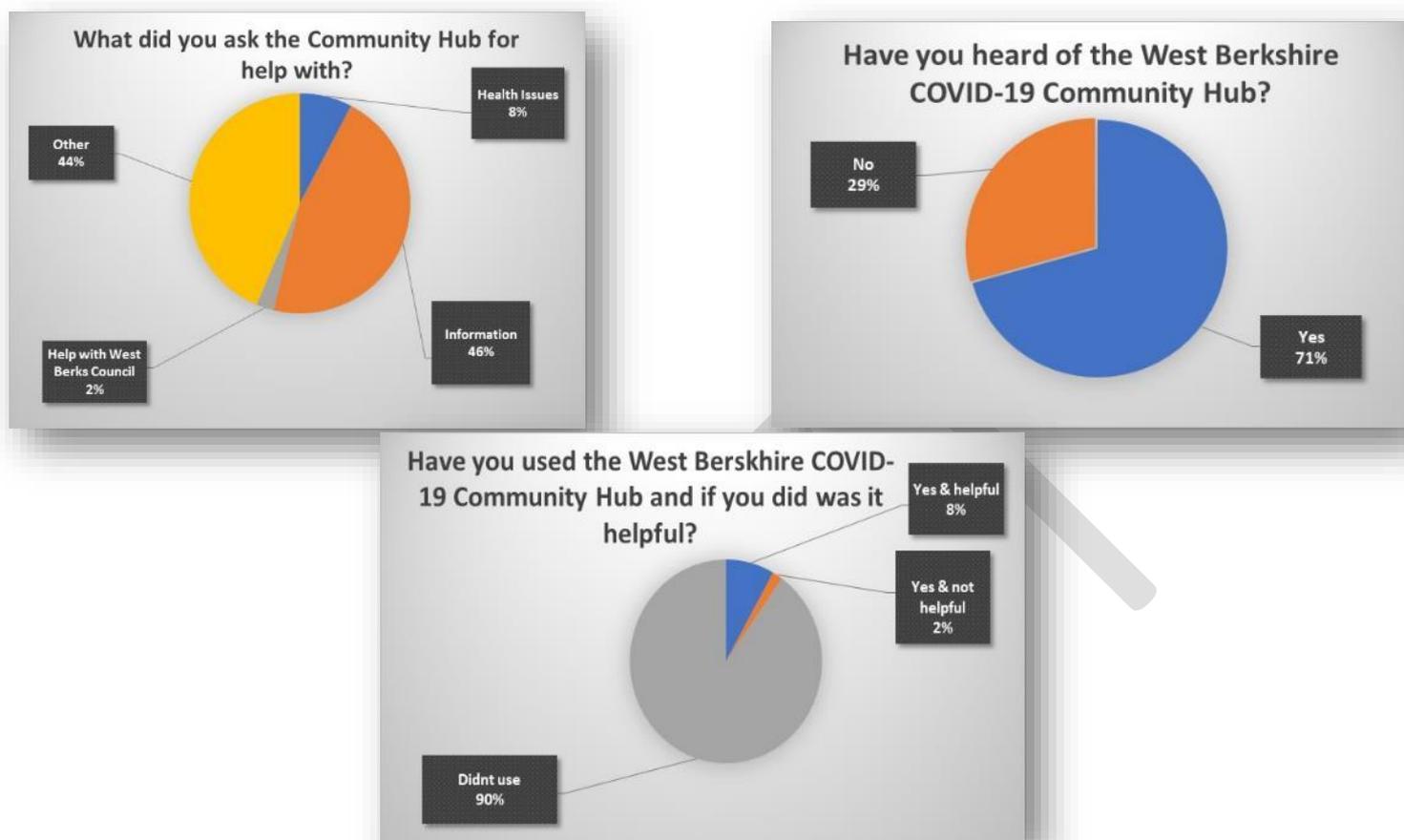
Which topics if any have you found it difficult to get information on?



Services Used



West Berkshire quickly set up a Community Hub to provide information about services and voluntary groups who could help/support people where necessary. This service was promoted through the council website, letters to residents' partners including Parish Councils, VS, local media, and a significant proportion of people knew about it.



Of the 301 who responded, more people found the service helpful than not with nearly half the respondents giving 'information' as their reason for contact.

“Can my relative go to the garden centre?”

“I want to stop the Government food parcel.”

“How can I volunteer?”

However, there were difficulties with access for some people to the hub.

“I registered to volunteer, but no contact made”

“I am a Home Carer for my Mum, 88 with Dementia & Heart Failure and I find it a mystery that her need for 35+ hours per week Care were not passed by the DWP to the West Berks Community Hub so I have had to be very proactive in my role.”

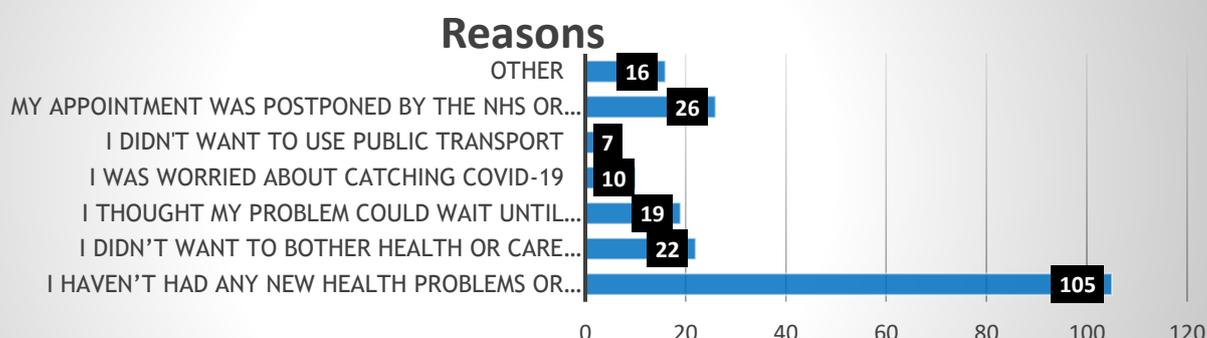
COVID TESTING/INFORMATION

A number of people found the distance they had to travel to get a test was too far and that getting results was problematic. This was not unusual more widely in the early days and much has been ironed out, particularly locally.

“I still do not positively know if I had Covid-19 after 4 months without an antibody test. It would have been reassuring to know either way, but I do appreciate the difficulties in having this done.”

“Testing for husband had to be in Oxford which meant a lot of travelling.”

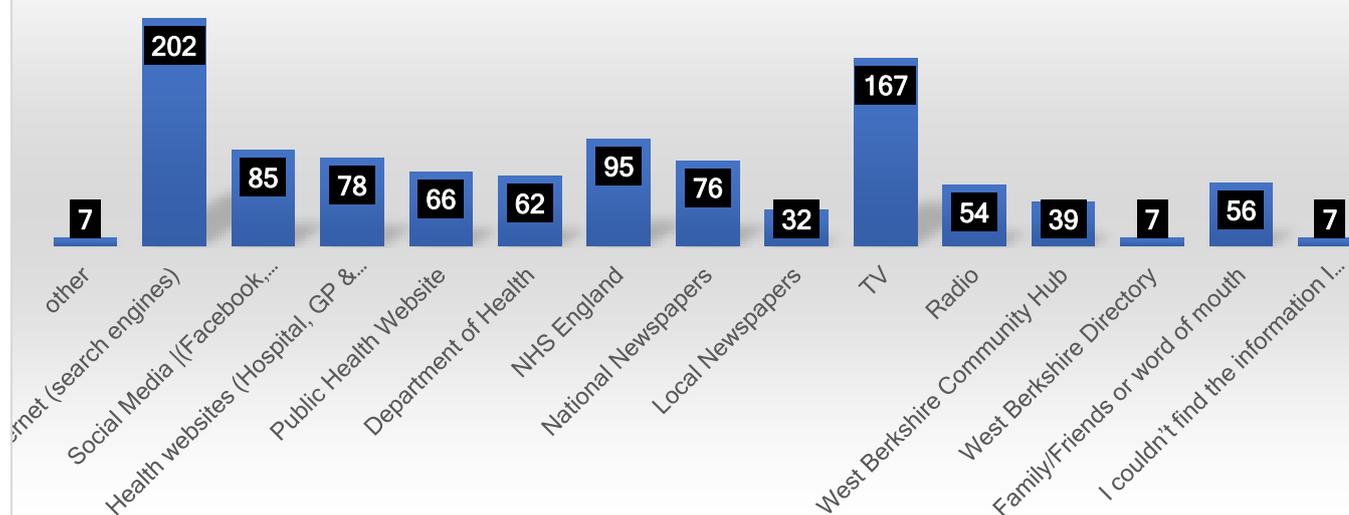
Reasons given why respondents did not access services varied. A significant number did not have any new health or care needs, which is heartening. Some appointments were postponed because of the pandemic and some people avoided services because of fear of infection.



Most respondents found information from the internet, with the television coming second, followed by NHS England.

GP services were the most used, followed by pharmacy and thence hospital.

Where did you find the COVID-19 Information



HOW PEOPLE FELT ABOUT THEIR HEALTH AND CARE SERVICES AND VOLUNTEERS - over 100 people left comments

In general people were very appreciative of the services they received and there is clear support for the NHS. Services are about people and the people who stepped up locally are a reflection of how things could be going forward if we can maintain the community and caring momentum.

The comments are too numerous to include here but please see Appendix 2.

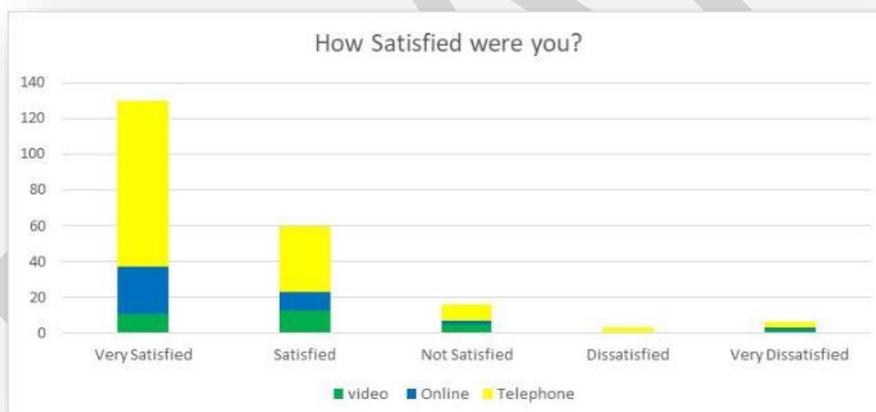
“Thank you, all the NHS staff, for always helping us.”

“Thank you to the pharmacists for keeping going.”

“Thank you to all our wonderful NHS who have kept working through the crisis, despite being underfunded, understaffed and under protected (due to the policies incompetence of the government) Additionally, thank you to the EI volunteers who collected medicines for us throughout the crisis.”

HOW PEOPLE FELT ABOUT THEIR GP SERVICES

In the main people were happy with the service they received from their GP and appreciated the difficult times.

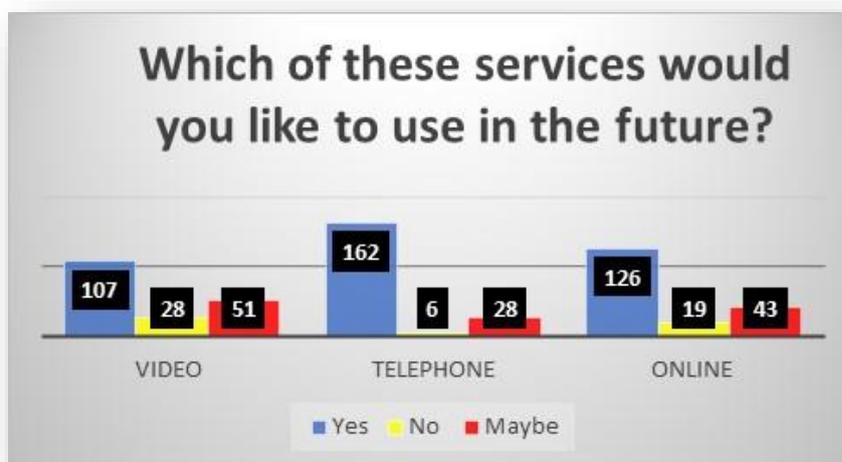


“I was given precise instructions of how to attend the surgery for my blood test and was taken in on time. They minimised my time inside the surgery.”

“Amazing care from my GP who called me every day.”

“I believe I got Covid-19 in March following a trip to France. Whilst not having all of the symptoms, I had significant breathing problems, fatigue, and loss of smell. So, I took Paracetamol and remained in bed for two weeks. I was still unable to fill my lungs fully after 8 weeks and wondered whether my lungs had been damaged by the virus. Having contacted e-consult, my GP arranged for me to have a chest x-ray and blood test at Basingstoke hospital. The blood test suggested I might have a blood clot, so I was summonsed back to the hospital the same day for further tests. The diagnosis was that I was suffering from Post Viral Syndrome since when I am feeling considerably better and reassured.”

It was felt that having the choice of a telephone consultation was good. Video consultations, where these took place, were also appreciated and it was suggested that there would be a benefit for the choice of these opportunities to be extended.



“Telephone appointments really work, and video chat would be even better.”

“Telephone appointments really work, an Excellent service. Spoke to my own GP. Had good consultation and prescription sent to my usual pharmacy, video chat would be even better.”

“Being able to talk the problem through was helpful and quick. Saving time for everyone.”

“Sent my query via email. My GP called me back. I am very happy with the information.”

“Providing options of telephone/video or face-to-face consultations was extremely good. As someone who suffers from a number of ongoing conditions, including depression/ anxiety it is helpful to have the option for telephone consultations, which are easier to deal with.”

The extended choice of a video consultation was mentioned as being something that would be appreciated. However, it should be noted that this is not for everyone.



“I had a telephone consultation which was fine, but I think offering video consultations as an option as well as phone would be beneficial.”

There were comments about some people appearing to not be concerned about safety and this causes concern.

“Not wearing masks in surgery.”

“Some people weren't social distancing.”

Unfortunately, one GP Practice had to close because of staff shortages, and this meant that it was quite a way to get to the sister surgery which caused quite some problems for some people.

“Disappointing that our village GP closed completely meaning that we had to travel 4 miles to our sister surgery for all prescriptions and appointments. Prescriptions took up to 14 days to be ready.”

There were also concerns about access to surgeries and waiting times outside, often in the cold and wet.

“On arrival I was expected to stand outside under a gazebo. There were no chairs provided. She raised this with the surgery after waiting 15 mins. No apology or provision of chair. Simple kindness lacking.”

GP access was mentioned as problematic.

“I think getting through to the doctors is hard enough but now it is even harder.”

“GP very slow to offer any help Just said probably Covid, call back in 4 weeks if no better... We did... And again, a month later.”

HOSPITAL AND EMERGENCY SERVICES

People were appreciative of services when needed although lack of communication was an issue for some.

“I had a scan at West Berks which went well. On time and very efficient.”

“Ultrasound scan - very efficient, with quick feedback both personally and to GP (Basingstoke Hospital).”

“GP telephone contact & Savernake Hospital Physio OPD were prompt & very helpful.”

“Rang as elderly neighbour fell 111 phone call operators was brilliant and sent ambulance.”

“Felt very safe at both Royal Berks and the Community hospital.”

“The nurse is kind and very helpful. She called me back when I mention to the doctor that I could not make an appointment at the fertility clinic at Maidenhead.”

“As result of cancellations. All went well. Hospital protection procedures very good. However I had a letter from rheumatology about self-isolation at the beginning of lockdown, but now it is ending, I have been sent no follow up information about what I should do. I have some dental problems, urgent but not emergency, and I can't get an appointment at all at the moment.”

“Better communications with family members of patients in hospital with Covid-19 and therefore unable to visit.”

“Some of the other patients weren't social distancing.”

“Not really, the only issue was that it took nearly as long for the ambulance staff to put on their PPE as it did for it to arrive! Totally understand the need for it though so it's not a complaint!”

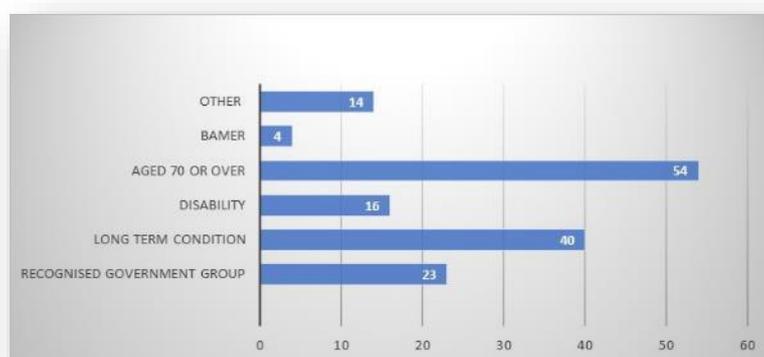
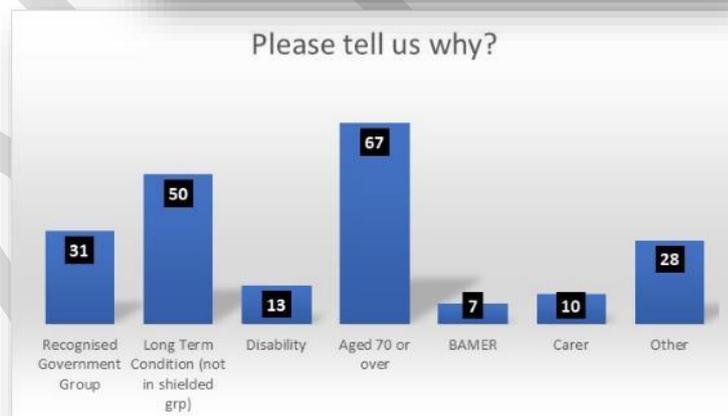
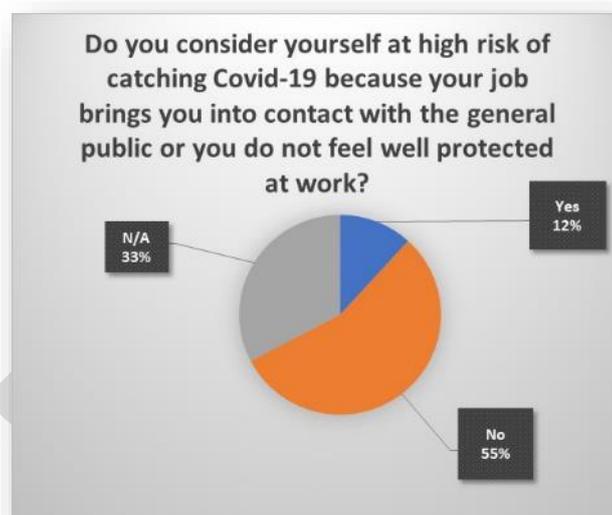
FEELINGS OF VULNERABILITY

A small number of respondents considered themselves to be at high risk of catching COVID because of their job. Roles mentioned included: Teacher, Waitress, Government, Volunteer, Complimentary Health Practitioner, Nursery Nurse, Ambulance Driver, Pharmacist.

67% thought themselves at high risk if they caught COVID-19 with being 70 or over causing the most concern. This was followed by those with a long-term condition but not in the shielded group (50%). A third were in a recognised Government group of which 89% had received a letter to shield.

73% of respondents cared for and/or supported someone who was considered to be at high risk with being aged 70 or over being given as the main reason followed by a long-term condition.

8% of cared for people had additional communication needs: British Sign Language user, Braille/audio/large print, Easy Read, other language, stroke survivor, learning disability, Downs Syndrome, hearing loss. Also, in this category are those with memory difficulties, dementia, or difficulties in understanding and/or retaining information.



PHLEBOTOMY

There were difficulties when bloods were an important part of monitoring a person's illness, as in diabetes. Delays have been evident because the supply of the necessary reagent was a national problem. One person was told to go to Bracknell but found that Royal Berkshire patients were excluded.

Currently there is a three-week delay for appointments which are taken on a priority basis and it is preferred that these are made online. For a significant number of people this can be problematic and is a digital disadvantage because they may not have access to hardware and/or not be confident with the technology. The current NHS view is that disadvantage people should seek the support of family and/or friends.

Burdwood Surgery is offering phlebotomy on a Sunday, but appointments are only being taken two weeks in advance.

Contracts with surgeries have ceased (except for Burdwood) but the phlebotomy staff were employed across the area so not an additional service.

This is an area where developing patients' confidence to self-test may be safer and easier and more resource efficient for both patients and GP.

"Bloods could have been taken at surgery which would have been a lot better and easier to manage than me having to travel to hospital where Covid patients were being cared for."

DENTAL

Throughout COVID-19 several additional services had to be closed, particularly dentists. The problem this caused was highlighted with us extensively.

"Orthodontists and dentists still haven't opened despite being allowed to due to shortage of PPE."

"I am waiting for dental surgery on the NHS which was cancelled. I have not received any form of contact from the dentist I was referred to either cancel the appointment or attempt to reschedule."

"Better planning for services like Dental, District Nursing, Blood tests."

"Dental appointment cancelled and now instead of having a filling the tooth will probably need to come out, which in my case need a general anaesthetic as can't open mouth wide enough for back tooth extraction."

"I was told that no new NHS patients are being taken on because there is a huge backlog BUT if I want to go private, I can be seen next week"

PHARMACIES

Pharmacies, a mainstay for some during phase one appeared to have some difficulties although there were also positive comments relating to out of area transfer. Going forward pharmacists are starting to be involved at surgeries to support GPs. Pharmacists have completed five years of health training so are an invaluable resource that has not been well used.

“I was able to have my prescriptions from London transferred quickly and efficiently to be collected in West Berks. My prescription was also extended to 2-month supply, which was extremely helpful. My assisted Covid test which I booked online and completed at Newbury racecourse was flawless - easy to book, impeccably managed, no queue and results returned quickly.”

“Medication was delivered the same day, by Neighbourcare, very efficient.”

“Yes. I needed an inhaler urgently, hence the 1st phone call and prescription was actioned quickly.”

However, some people felt ...

“Chaotic prescription process from GP to pharmacy led me to change to online pharmacy which is much better. They chase the GP whereas local pharmacy doesn't.”

“Pharmacy - tell you order is ready you get there to find stuff missing and need to go back next day. They advise you it now takes 7 working days to process your repeat prescriptions. Unacceptable time.”

“Would have been better if the pharmacy allowed people to have prescriptions delivered.”

“Pharmacy could be open to providing urgent meds when go has said they need to be provided same day, instead of refusing.”

CARERS

Vulnerable people were disadvantaged during phase one although the voluntary sector stepped up to the mark magnificently and the kindness and support was very much appreciated.

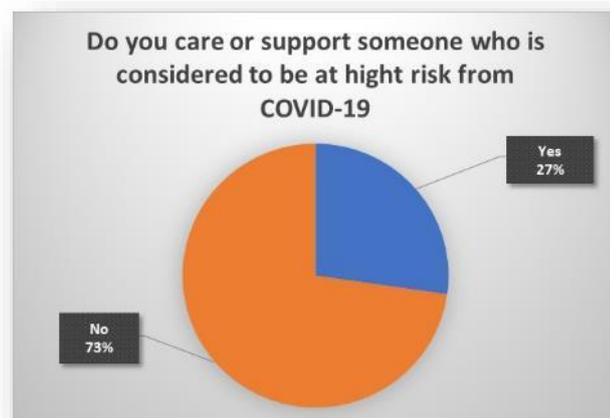
“Carer of my son and his wife who have Down's Syndrome. Excellent from someone employed by Mencap.”

However, there were particular difficulties for these vulnerable groups.

“For the first District Nurse visit she had no PPE. On the 2nd visit her apron was very flimsy. My daughter was more scared of her than she was of us. I am surprised that I was not identified as needing shielding as I receive full rate attendance allowance and my daughter receives the Carers Allowance.”

“I had to go into the equivalent of shielding to be one of two people shielding a third person. The one in need of care has been forgotten about. Nobody seems to want to know or care about him.”

“With Complex Mental Health Needs/Learning Disabilities - no real support for him because his needs are “too complex”, but he is intelligent & persistent enough to keep



on "knocking on doors" to access help - has eventually had 2 lots of "Talking Therapies" over the last 15-18 mts. Interestingly, when he most needed help following an emotional breakdown session a year ago, which led to someone else contacting 999/police for help, he had 3 visits from the CRISIS team then the Mental Health Senior cancelled all help for at least 3mts!!! I do find support from the Mental Health Carers Support Group."

Where the usual support for carers was suspended there were particular difficulties, and this requires attention in the following phases of the epidemic.

"Difficult circumstances but I would have liked to have had some respite, once a week for a couple of hours, but not sure how it could have been possible I had contact with the mental health crisis team which was helpful until I found I could not tolerate the medication I was given and was criticized for stopping them and they were angry with me making me even more suicidal by their attitude."

"Registered Carer for adult son with Complex Mental Health Needs/Learning Disabilities - no real support for him because his needs are "too complex", but he is intelligent & persistent enough to keep on "knocking on doors" to access help - has eventually had 2 lots of "Talking Therapies" over the last 15-18 mts. Interestingly, when he most needed help following an emotional breakdown session a year ago, which led to someone else contacting 999/police for help, he had 3 visits from the CRISIS team then the Mental Health Senior cancelled all help for at least 3mts!!! I do find support from the Mental Health Carers Support Group."

"I have Bipolar Disorder, a genetic weakness to stress and Anxiety. I am a carer to my husband and waiting to hear from the Autism Assessment Triage Team at CAMHS about both of my daughters. The not knowing when any help may be available, and the lessening of support within their school community has put extra pressure on me."

POSITIVE ASPECTS OF COVID-19

Some people felt that the initial lockdown was an opportunity to slow down and do some of the things that they had previously had little time to do. Some valued the time that being furloughed offered to spend time with family. For some children/young adults who were on the autistic spectrum there were reports that being at home was a positive experience, whilst for others this was a break in the usual routine and so was problematic.

"The quietness of all around, being able to hear birds, nature and having the time to spend in the garden."

"Initially I was worried about catching Covid 19 but as time went on, I became less worried and found plenty of things to do during lockdown such as gardening, walking and cycling which helped my mental well-being. Also time to do DIY etc which made me feel happy and satisfied."

"I am lucky to have space and a garden, so have found the peace and quiet from less cars, no planes, and more relaxed daily living very nice! I appreciate I am very fortunate and that so many people have had a very different experience."

“Have enjoyed life slowing down and having time at home with my family without pressures of work (both my husband and I were furloughed allowing time for life to catch up!”

EFFECTS ON FAMILY MEMBERS

The knock-on effects on family members where lockdown meant sharing space and/or being around people for a greater length of time caused difficulties for some.

“Just very hard never having any personal space/ time alone at home, nor seeing my family (parents, brother etc).”

“The restrictions not accounting for having several isolated family members who live alone. This causes a huge burden of communication on me and leaves me unable to provide what they crave - physical contact with another human being. In fact, at first it prevented even visual contact. In a lack of understanding that some families had no childcare for children at and under school age and two parents who were still working full time. Creating an impossible situation. There was no guidance as to how to cope with this situation.”

CHILDREN/HOME SCHOOLING

Home schooling was of considerable concern and the strain this put on some families, which remains where children are sent home due to some showing COVID symptoms. For children with additional needs and those who were struggling to keep up anyway this group is extremely disadvantaged as are those who do not have access to technology. Schools bring a routine and a structure that many found losing to be very stressful.

“3 young children (none of whom want to do any schoolwork, or cooperate with each other, or help do anything around the house, one experiencing symptoms of autism and not coping with lockdown or being near his older brother at all, eventually regressing back into nappies despite being fully trained for 2 years) and husband works away. I could go on, but that is just the tip of the iceberg.”

“I am a single mum with a 9-year-old. I rely on community clubs, kids' activities and clubs, leisure centres and parks just to get by during the week. I do not have many friends or family support so being able to go to group activities is crucial for me. Currently I am at home home-schooling, and the constant 24/7 at home with nowhere to go (apart from walks) is really getting to me. I absolutely hate it. And it is not yet clear if these types of activities will open up again even after Sept. I really don't know how to keep myself mentally healthy if these groups activities don't start up again soon.”

“Attempting to keep up with work and home school children at the same time has made the last few months relentless. I feel exhausted and like I am not doing my job to the standard I would usually achieve.”

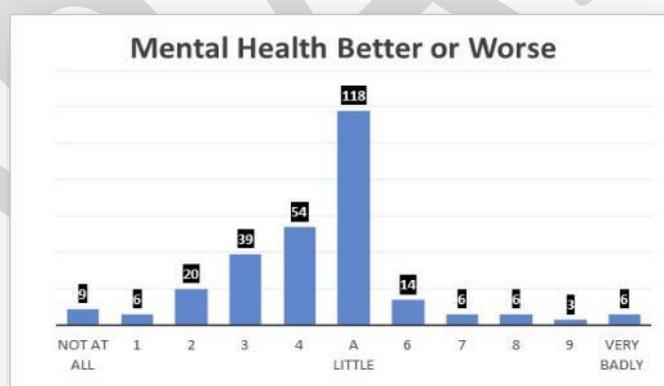
“All school structure disappearing overnight, felt lost, didn't know what I should do anymore.”



MENTAL HEALTH

Mental health difficulties have been reported Nationally as rising during COVID-19. In this survey, 59 respondents said they had a little difficulty affected by COVID-19 with 118 saying it was made worse as time went on.

“My eldest daughter went into isolation with me, and the District Nurses came for essential blood tests, albeit less frequency. My daughter used the Community hub and arranged for food to come and prescriptions.”



Reasons given included: (please see Appendix 2 for all reasons)

“Inevitable anxiety. Trying to process the information and statistics associated with the Covid virus.”

“Lack of access to the communities I belong to eg via U3A, health club, lack of access to health.”

“Not being able to see my parents or favourite colleagues easily”.

“Isolated.”

“Initially having to share space with husband working from home. Husband also not talking.”

“Concern and anxiety about delayed health assessments.”

“Unhappiness about not being able to do planned & booked leisure activities and plan and goon holiday.”

“Previous anxiety around driving resurfaced as I hadn't driven a long (50 miles) distance for 3 months.”

“Isolation is used as a form of punishment and it's torture and to see people breaking lockdown rules makes you think why bother.”

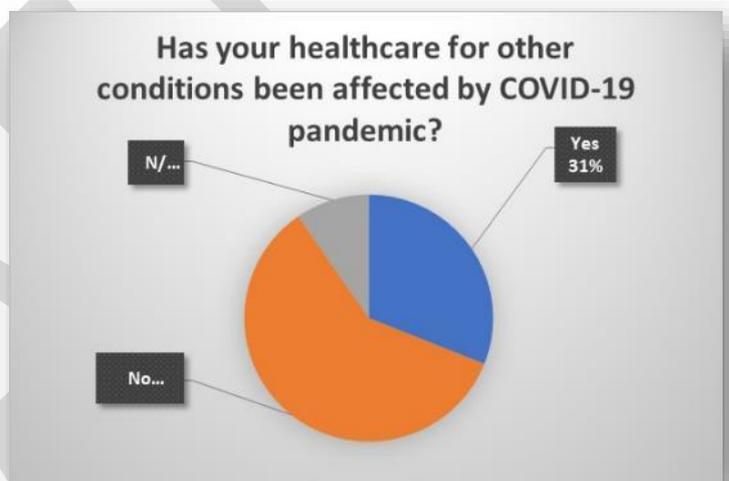
“Crave - physical contact with another human being. In fact, at first it prevented even visual.”

“Under school age and two parents who were still working full time. Creating an impossible situation. There was no guidance as to how to cope with this situation.”

“Widowed 2016 and comfortable with living alone in right house, but less resilient than expected with lock-down and distant family.”

OTHER CONDITIONS AND COVID-19

A significant number of respondents had surgery and/or appointments postponed or cancelled. This has been reported Nationally and there is now an awareness of the delays, etc as an issue. However, it is relevant to report the problems experienced locally.



“I need a hearing aid but the appointment to fit it was cancelled I need a knee replacement, that has been delayed indefinitely I have had a referral for physiotherapy that has been delayed.”

“Cardio appointment postponed.”

“Investigations of raised Ferritin levels put on hold. Difficulty obtaining meds. Lack of unsolicited info about whether I'm high risk due to Lymphoma.”

“Awaiting ambulatory EEG test for epilepsy, was expected in April but not even heard from hospital. Asked for phone call from consultant but not rung back.”

However, for some people a delay or altered intervention was not a problem.

“Delayed additional incisions following melanomas. Changed lymph node removal to ultrasound. (It was explained, and I am happy with this.)”

“Delayed operation but does not make a great difference to everyday life.”

BEREAVEMENT

People affected by bereavement, whatever the time since their loss, have often felt marginalised. Deaths from the virus leave loved ones often feeling guilty because they were prevented from ‘holding a person’s hand’ or ‘being there’.

“The death of my husband from coronavirus, whilst going through the illness myself.”

“Lost my daughter to lung cancer very suddenly last year and lockdown has coincided with many painful anniversaries.”

“My husband died two years ago, and I’ve found the loss very hard. It is particularly hard now because being confided would have been so lovely. I also hear lots on the media about bubbling, but I don’t have anyone to bubble with.”



THANK YOU

Healthwatch West Berkshire would like to thank all the members of the public who took the time to fill out the survey and everyone who has been in touch to feed back about the services in West Berkshire.

Thanks to board member Karen Swaffield for co-authoring the report and all of our amazing volunteers and board members for their help.

APPENDIX 1 - ADDITIONAL QUOTES TO TEXT INCLUSIONS

MENTAL HEALTH POSITIVES

Has not changed	I have been fine at home	Hasn't changed at all	No change in my mental health
Getting out in the garden daily when the weather was good. Also time to do DIY etc which made me feel happy and satisfied	Kept active physically and mentally reality of life alone as a widow	Out walking a lot	Life is less confusing in some ways because it has been lived in one place without appointments and deadlines. I've missed socialising
Despite living alone and not going out I have kept in touch regularly with family and friends via video and phone and have done regular online exercise classes	Not being required to commute, able to work from home. Luckily, I'm a resilient personality and just get on with things but others may not be so resilient!	Spending real time with my family and trying new things out plus being able to continue my job	Furloughed, lack of control
Nothing much, but lockdown is depressing. I'm 75 and the future does not look attractive	Slower pace of life. More time to relax and undertake jobs that bothered me around house and in life, better sleep, better work/life balance	Less stress working from home	They advised focussing on books and music rather than the news. So I took up a new music-based hobby and this has really helped me. I feel far better now
Getting mentally ill on VE Day - getting temperamental and losing sleep and concentration. So I contacted the Samaritans by email. They helped me gather my thoughts in a positive way	Control yourself, talk to the people, exercise, be in contact with the family	Not having to commute	Taken more physical activity
Not so much pressure to get basic things done so we can get involved in social activities. Less stress as we can't do childcare for grandchildren is the biggest factor but also stressful not to be able to see them as they have cystic fibrosis so are shielded	Being on furlough has given me quality time with my family, spending more time gardening, maintaining house and exercising, my eldest child came back to live with us for 8 weeks, and I haven't had to go to a job I don't like much. I haven't enjoyed having to socially distance, though we have been good, and idiots in eg supermarket on essential shopping trips have been annoying. I have liked seeing good changes eg more people out walking as a family, no airplanes, less pollution. But now that's all changing. I haven't liked holiday plans changing, which stopped me scattering my mum's ashes	Less demands on my time, less responsibilities. It's been like a long holiday a complete break from usual routine has been refreshing	

MENTAL HEALTH CHALLENGES

Relative isolated in a small studio flat with no garden. Felt he could not go out. His social life is usually a walk round the shops in town	Lack of access to the communities I belong to eg via U3A, health club, lack of access to health and life enhancing activities normally available to me	Not being able to see my parents or favourite colleagues easily	Anxiety for others (my own children, NHS staff) balanced by improvement in my own routines, slowing down
All routines taken away no support	Too many unknowns increased anxiety. Being at home and unable to have time by myself to relax. Working from home under conditions that are more stressful than at work!	Worry about those people not coping and what will happen to already disadvantaged people following Covid	I don't know I have Dementia and know there is a Plague so I cannot go out in my daughter's car for our rides to the countryside
Isolation. Not being able to go out or see friends and family. General lack of stimulation	I have had some minor health issues which have added to the anxiety, and feeling I am on my own	More anxious about going out. It would be good to know the local risk AM I over worrying about the risk of shopping	Work has been more stressful-managing others anxiety Then knowing I am the risk to my family not using school as needing to limit additional risk
Just a bit lonely / I am not sleeping well	Worry about the future Juggling too many responsibilities (home school and increased workload due to COVID-19	The loss of being able to just go out and see people	Lack of socialisation Fear for my partner and children who are high risk Having to work full time and home school 4 children in 3 different year groups
The stress of keeping the kids occupied and being unable to go out to see friends	Not knowing you are doing things correctly and the guilt that comes with that	Support of friends and family. Christian Faith and advice from a counsellor (private)	Bit stressful with the kids lack of face-to-face social contact. family member died and I couldn't visit them, have a proper funeral and wake, can't go through grieving process
Being furloughed and unable to work. The unknown, pressures of home-schooling and keeping family safe, Not seeing family members. No income as partner made redundant. Have suspected coronavirus	Anxiety, bereavement, changing routines, uncertainty about the medium-term future, inability to plan, not able to get to outdoor places, theatre or church which are usually the places I go to unwind.	Anxiety of the unknown, fear of going to supermarket any kind of possible contact. Media stories, had to remove myself from social media & watching news	Started a new job. Was furlough after 15 days. Job now at risk of redundancy. No respite from my caring responsibilities. Less exercise. Eating worse. Increased anxiety around risks to loved ones
Lack of social contact and no church though we do have online.	I live alone - lack of face-to-face contact, hugs etc. I don't think I realised just how vital it is that we are able to see and touch each other	Shielding relative	Living on my own in isolation (my children live abroad, and my brother lives two hours . the only family I have)
No respite for 2016 hours as isolated in a house with my Demented mother	Lack of information on when I will be able to have the investigations, I was referred for in	Illness myself and unable to access help with caring for children etc	Thoughts of returning to work with no childcare (recept age, currently attending school 10- 14 on Mondays and Fridays)
Missing my friends and family. Not being able to hug them	Unable to meet with friends and having to stay with the children 24-7. Nowhere to get head space	Miscarriage and too much time to think	Living with someone who suffers with extreme anxiety and occasional paranoia

Unable to meet with friends and having to stay with the children 24-7. Nowhere to get head space	Miscarriage and too much time to think	Living with someone who suffers with extreme anxiety and occasional paranoia	Isolation from family members
Sanity Measures - non Covid time - are many social (plus voluntary) activities (Foodbank volunteer & Volunteer Theatre Usher) plus many Folk-Dance Activities (evenings/weekends/weeks away). All now inactive but catching up by email & phone. Zoom meetings for Church Groups I have volunteered as a Phone Contact for those isolated/Shielding. Now more time at home with a complex mental health needs adult son - can be tense, generally ok, but increases stress.	February. Worrying about whether to chase the GP practice or radiology department Isolation was my biggest fear. Being alone for long periods of time made me anxious and everything lost its meaning. The coping strategies I usually use to manage my mental health were taken away. Leaving my flat for a while when I feel anxious helps. Not knowing whether things would ever be 'normal' again made me very anxious	The death of my father during lockdown. Not being able to meet people in support group. Not going out so finding hard with sleep and tackle depression anxiety. As a family not being able to all meet up and grieve properly. Feeling of isolation as not meeting for mutual support with friends. Just not the same only phone calls miss physically being in the same place as others as this helps with depression	Not being allowed face to face contact with friends and family. Worries over how my children are coping (both primary school age). Worries over my brother who lives alone. Feelings of sadness due to not being allowed to do my job or any of the social activities or types of exercise that I would normally do during my week. Anxiety over having to go the shops due to social distancing rules - every shop does things differently and trying to keep up with opening hours, one way systems, queueing systems both outside and at checkouts, how to pay, checking whether hand sanitiser is provided at the shop entrance and whether it's optional or essential to use the one in the shop or if I can use my own, whether I can go with someone else/on my own/take a child, how to get past someone blocking a narrow aisle, the list goes on and on
Boredom, anxiety, news overload at the beginning when I was watching or listening to everything I could find. Worrying about family not living with me, especially when they contracted mild COVID19, and we're on their own at home	Diagnosed with cancer, and not knowing whether early diagnosis or spread. However, a series of tests done within 4 to 6 weeks, which in comparison to national average was excellent but 3 weeks would have been possible as the team probably knew which test, I would have to have, from the very beginning	Just because I have not been in contact with other carers and have been unable to go out and meet friends, which means I have been with my husband 24/7 without me time	Missing family and friends. Access to normal dance classes. Unable to hold my own yoga classes. Video is not the same, live or recorded.
Lack of access to activities that improve my mental health. Staying home has given me lots of time to dwell on negative thoughts	Inability to hug friends and family	Very anxious about catching covid, not enough information about the risks locally	Difficult not seeing family, especially our granddaughter
Limitations on social contact. Loss of access to gym	Not being able to go out and see friends	Worried for family and friends. Also have lost a friend to Covid19, aged 63 with no underlying health issues	Lack of confidence in the government due to perpetual lying, which means I feel uncomfortable about going out and about
Initial isolation and lack of outdoor exercise was hard to accept then once restrictions lifted concerns about social distancing Even in streets and parks. So many people seem unaware of correct procedure	My being tactile and my visual impairment making it harder to observe the social distancing rules and people ignoring the social distancing by walking too close to me	Lost my daughter to lung cancer very suddenly last year and lockdown has coincided with many painful anniversaries	I think it's anxiety about what will happen to my children & grandchildren in years to come rather than thinking of myself
Difficult not seeing family, especially our granddaughter	Knowing I couldn't go out, feel like I was getting cabin fever	Worry about health	Level of pain from hip problems
The pressure of running a household of 5 people, working and home-schooling. The worry about friends or family getting ill. The lack of food in the beginning.	Concern about financial situation due to potential job losses. Anxious about going to shops as many people do not wear masks or social distance	Whilst I try to stay positive it is a difficult time re families/work and the future, sometimes feel abandoned by health services	The worry about catching it, also living alone and dealing with things n my own is harder anyway, coming out of 3 years of cancer treatment doesn't help

Loneliness / Adaptation Isolation and lack of personal contact with family and friends. Lack of freedom to go where and when I wanted	Just isolating at home was difficult. Going to shop weekly to get food was somewhat stressful and still is rush of life has slowed down, more compelled to take care of myself	Poor Government handling of crisis utterly amateur and corrupt over ventilators/PPE/testing	I now feel more introverted than before. Contacting anyone (even friends and relatives) feels more difficult now
Raised anxiety leading to lack of sleep. Mainly as unable to support	Stuck indoors all day with limited interaction with others	Being stuck indoors at times	Isolation and conflicting instructions
Anxiety	social contact outside of my family	Anxiety about other family members	Loneliness and fear It's primarily the panic due to media.
family and friends face to face, and not able to access my regular exercise at the Leisure Centre.	Fear of the unknown. Social isolation. Loneliness	Worry about catching the virus or having it with no symptoms and passing it on to a vulnerable person ie my parents	Forced me to finally give up teaching Adults which I love, not being able to see and cuddle my family, delays in my treatment
Feeling isolated from family members	Self-Isolation for not able socialise with family and friends	Am better now I can see my family, but was distraught at the beginning because I missed my family so much?	Being forced to stay at home and slow down daily life helped, spending time with my children.
Constantly being around family and having to home school	Anxiety has increased considerably worrying about my health and that of family members	Don't know, probably the isolation	Not able to go out and see my friends, Negative messaging everywhere Death
Being self-isolated, alone at home	Uncertainty, mixed messages	A little worse for not attending Gym	Confusion from Prime Minister and stopping of daily TV
Well, reading the news and graphs about COVID made me very depressed. I was obviously	Being alone and not in contact with others can make people feel lonely	Postponement of Op. Restricted Shopping trips to Supermarket and Garden centres. No visits to DIY and other shops. disruption to regular routine	Lack of info Family member dying in Newbury Care Home No info from local MP
Being locked in our home was a change in the routine and my daily life. Not being able to go out and seeing family/friends	Overall anxiety about isolation Anxiety about keeping myself and those I care about safe and well	Being apart from my parents and daily worries hasn't helped though.	Concern about transmission of the virus by others not taking care to isolate, sanitise etc despite family members asking her Level
Particularly my daughter, as she works as a Respiratory Physio in a hospital. I feel quite concerned about the future. I am now experiencing a resurgence of depression, which I have had before	Only some mild concerns about future and I am just under 70 with asthma so I took the recommended precautions	As a widow with no siblings and no children I feel forgotten about. There seems to be a lot of talk about children and grandparents but not a lot of provision for people in my circumstance	

Appendix 2 - Messages of Thanks for the NHS/Keyworkers

Overall good support during the lockdown and NHS supports nicely	Chapel Row Surgery for the efficient and safe apt with the Phlebotomist - Maria - and to their staff in their Dispensary for safe & well organised collection of medications	Boots at Thatcham Medical Centre and Boots Northbrook street really helpful and it felt safe going there.	Big hugs and love to all working for nhs.
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Church st practice wantage was fantastic on the two occasions that I visited them. Lloyds pharmacy wantage are fantastic.	I would like to thank Dr Emma Alcock and Sian Robinson at Hungerford Surgery - amazing but then all the staff at Hungerford surgery are too.	Shared lives officer in Newbury was so kind, looking out for us , giving her time with care & kindness.	I have been well looked after by my surgery. Reception/pharmacists everyone helpful.
Hungerford GP surgery. The telephone appointment was quickly arranged and answered my concerns as well as a face-to-face appointment would have done.	Kintbury & Woolton Hill staff, especially the reception and pharmacy teams, have been amazing.	Orthopaedic team at NHH for putting my concerns to rest.	Our GP practice has been exemplary.
My thanks to GP surgery reception staff	Dr Graham Stiff at Strawberry Hill was professional, friendly, thorough and inspired keeping well	District Nurses GP - Strawberry Hill WB Community Hub Boxford Parish Clerk and Volunteers Group	Thanks to pharmacy and volunteers for deliveries
Thank you to Jackie Scott Epilepsy Nurse for taking so many calls and helping to get swab arranged when system said no! Thank you to Jason, Danielle and Kate in RBH A & E for being so kind to special needs person during very stressful time.	I was very impressed with the response at the surgery and the follow up call from Dr Helyer. Also, I was very pleased with the response which I got from the Neighbourhood care team when they arranged for my meds to be collected and delivered to my home.	Very caring and helpful care from Dr Hardwick of Chapel Row Surgery and All the nurses who visited.	WELL DONE to all! Just think the government could have done better!
Thanks to all those at RBH, JR and Windsor hospitals for care for detached retina.	It was the woman on the 111 line who laughed - with me, not at me - who made me feel like a real person and not just another phone call	Chapel Row surgery seem to be managing telephone appointments well!	Day Lewis Pharmacy Newbury next to the Strawberry hill medical centre. Absolutely brilliant and go above and beyond.
Thank you to the Thatcham Family Hub, especially Rhys Lewis. Also huge thank you to the team at West Berks Minor Injuries. Can not thank you all enough for the exceptional help and the sacrifices you have made.	Thanks to all at Eastfield House surgery, very helpful	Thank you SO much to Dr Howells at Kintbury, and also to the doctor and nurse who saw me at Newbury Racecourse. Covid 19 was very frightening, and I felt taken care of and reassured - you were amazing.	Woolton Hill surgery responded extremely quickly to a problem that my husband had. Thank you!
I like to thank all at the Thatcham medical practice, especially Dr Mothram who has helped my mother in-law over this period with bowel and lung cancer. Also, the staff in Riyal Berkshire hospital and tower bridge hospital who have been so caring for her when we can't be there. Amazing people and have saved her life.	Neighbourcare Community Support which sprang into action early and has helped the surgery with delivery of medicines and had numerous volunteers who can be called upon for help with individuals as needed.	I would like to say a big thank you to Kirsty Crozier at the Churchill Hospital, Oxford who has been at the end of a telephone or with a quick online response to any questions I have asked regarding my treatment, my drug deliveries, my appointments, or anything else I have raised. She has been wonderful.	Eastfield House surgery have been brilliant. I see the nurses regularly and there has been contact with them when I have not been able to go in. I have been in contact with Anna Bird, the social prescriber. She's very nice.
Boots Chemist Thatcham - for continuing under great pressure and risk to themselves. One member of staff was going home she saw how long the queue was and went back in to help sort it..	I would particularly like to thank the Pharmacist at my local surgery for her assistance plus the other members of the prescriptions department and all the staff at the Practice.	My surgery was The Burdwood Surgery, they are always great however I wouldn't want to single anyone out, we have a fabulous NHS staff/service who always deserve our gratitude and thanks.	- Bin men who came every week during lockdown NHS staff for everything they do especially during lockdown All teachers that continued throughout lockdown

Dr Rutter at Burdwood Surgery was amazing and really took the time to understand what was going on with me and do what she could to help.	Thanks to Falkland surgery nurse pharmacist and to reception. Thanks to Basingstoke Hospital A and E team	THANK YOU to everyone working on the front line ... you have all been magnificent and gone above and beyond your remit.	Thatcham Surgery were amazing. Swift ring back on two occasions, great online consultation and sending prescription to my local pharmacy immediately.
Thanks to the Community Nurses, Surgery & Community Hub	Allergy Clinic at Frimley Hospital - spoke to a very lovely doctor.	Overall good support during the lockdown and NHS supports nicely	Thanks to paramedics Daniel White & Tom Simcox from South Central Ambulance Service. They were just great!!
I'm awaiting a dental appointment as I lost a crown at the beginning of lockdown but fully understand that this might not be possible for some time. Luckily no pain so far.	Estelle Fox-Masters at Richmond Fellowship, Garland Court for being friendly, patient and understanding.	Thank you so very much to all working for the NHS during the pandemic	Very grateful to see doctor at Thatcham Health Centre for what was a very little thing compared to what they were having to cope with. Thank you!
Dr Christine Corder at The Burdwood Surgery	I just think the NHS has done a great job over this pandemic in very difficult circumstances.	The NHS has been and still is fantastic and now is the time to rectify some access issues so that we all can use its services effectively	Huge thanks to trauma orthopaedic at west Berkshire hospital and the day surgery team - amazing service. Felt very safe
The Pharmacy at the Downland Practice has adapted very well to life during lockdown. The staff there have always been very polite, efficient and eager to help.	Thanks to all Community Hub volunteers and staff providing support in delivering food boxes, hot food and prescription to the needy one during this crisis- Well-done	COVID 19 has made your lives hell. Don't waste this chance to really make great changes - a real digital driven revolution is now possible. Grab the opportunity	I believe the NHS have been incredible although G. Ps need to improve the service
Thank you to Chieveley surgery and Oxford Churchill Hospital day surgery unit staff.	Thanks NHS and all key workers Also thanks to west Berkshire health watch for organising this survey	Thank you to Burdwood Surgery. Very helpful and efficient staff. A particular mention for Nurse Julie fo being so helpful and friendly.	I would like to thank all the staff involved in helping Covid patients and their families and wish them a safe future.
Big thank you to g p practice and all staff from cleaning staff porters and all medical staff stay safe god bless all of you	Tadley Medical Practice, The Candover Clinic and North Hampshire Basingstoke Hospital, especially the Ambulatory Care Unit.	I really appreciated 111 when I spoke to them, they were so supportive and helpful and issued the antibiotics I needed.	Thank you to Dr Bahia at Burdwood Surgery who listened and understood my concerns and took the time to call me back as a follow up.
Downland Practice Surgery for safely, efficiently and with a smile dispensing medicine	Thank you to Dr Bahia at Burdwood Surgery who listened and understood my concerns and took the time to call me back as a follow up.	I'm very grateful to our amazing NHS, Health Care Workers, keyworkers and volunteers who have kept our country running.	Many thanks to Strawberry Hill Medical Centre Dr Irfan - very swift reply about blood test.