

Carer Strategy Engagement

– Summary of Secondary and Primary Research

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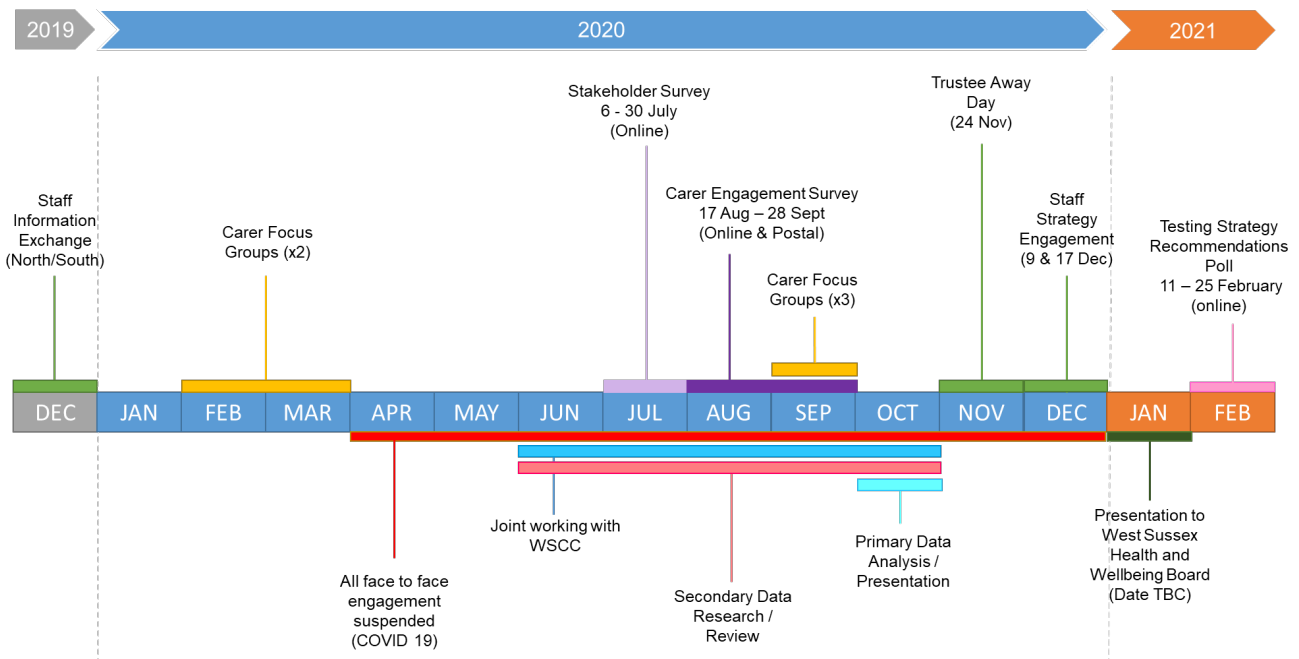
Carer Strategy Engagement Overview

Carers Support West Sussex (CSWS) started work on strategy development with staff in December 2019 (revisiting Vision, Values and Strategic Aim) and engagement with carers in February/March 2020.

In June 2022, we commenced joint working with West Sussex County Council (WSCC) Carer Commissioning Team for the purposes of updating the *2015 Joint Commitment to Carers* memorandum for the county.

Secondary data (local and national reports and survey findings¹) were reviewed between June – October 2020. With primary data (online and print survey launched, and carer focus groups hosted) results being collated and findings presented in October 2020.

Timeline



2019

December CSWS Staff Information Exchange (North/South)

2020

February Carer Focus Groups (x2)

June – Ongoing Secondary Data Research Review

July Stakeholder Survey, 6 - 30 July (Online)

August – September Carer Engagement Survey, 17 Aug – 28 Sept (Online & Postal)
Carer Focus Groups (x3)

October Primary Data Analysis

November CSWS Trustee Away Day

December CSWS Staff Strategy Engagement Sessions (x2)

2021

February Testing Recommendations Poll, 11 – 25 February (Online)

April Carer Focus Groups (x3) – Testing Recommendations

¹ URL links/sources cited accessible at time of publication (April 2021)

Secondary Data Review

A desk-based analysis was undertaken by reviewing existing data and information (i.e. surveys and reports) to enable a broader understanding of carer related issues, both locally and nationally.

Local

1. West Sussex Joint Commitment to Family and Friend Carers 2015 – 2020 (2015), West Sussex County Council

Overview

- Produced by WSCC in partnership with the three Clinical Commissioning Groups (Coastal, Crawley and Mid Sussex).
- Set out the public commitments on how organisations should work together to identify and support carers in West Sussex over a five-year period (2015-2020).
- Commitments were set around the following five themes
 1. To raise the profile of carers/young carers – make carers part of everyone’s core business.
 2. To achieve personalised support to carer.
 3. Ensure young carers do not carry out inappropriate levels of care and can achieve in education and employment.
 4. Support carers to remain physically and mentally well.
 5. Build a carer friendly community.

Measured Progress

According to the Health and Wellbeing Board March 16th, 2020 meeting, progress against the five commitments were last reported in June 2018.

Commitment	Progress (as of June 2018)
1. To raise the profile of carers/young carers – make carers part of everyone’s core business.	Registration increased by over 60% in the past five years (around 250 to 300 new carers registered every month)
2. To achieve personalised support to carer.	Around 80 full statutory carer assessments completed per month (pre-2015 figure was around 45 to 50 assessments per month)
3. Ensure young carers do not carry out inappropriate levels of care and can achieve in education and employment.	Young carer referrals over the last 4 years increased by over 80%.
4. Support carers to remain physically and mentally well.	Promotion of a ‘Think Carer’ perspective. Carer Support Workers now based alongside NHS staff in every acute and community hospital.
5. Build a carer friendly community.	34 businesses joined the Employers for Carers initiative via WSCC. Launch of Carer Discount Card to help carers save money and enable carer friendly businesses and communities.

Source: https://www.westsussex.gov.uk/media/6396/joint_commitment_to_carers_report.pdf

2. Survey of Adult Carers in England (SACE) 2018 - 19

Overview

- In 2018, 1200 carers were surveyed as part of the two-yearly Survey of Adult Carers in England 2018-19.
- 568 (36.3%) responses were received.

Summary (%) of responses related to West Sussex carers only are presented below:

SACE 2018-19 Questions	%
Overall satisfaction of carers who had received support and services - very or extremely satisfied	41.7%
People who have been carers for more than five years	54.0%
People who have been carers for more than 20 years	15.9%
Carers reporting that caring had caused them feelings of stress	65.2%
Carers reporting financial difficulties caused by their caring role - no financial difficulties	52.2%
Carers reporting financial difficulties caused by their caring role - a lot of financial difficulties	9.7%
Carers who found it easy to find information about services	71.6%
Carers included or consulted in decisions about the person they care for	70.05%
Carers with as much social contact as they would like	35.9%

Key Findings

Top issues for Carers

- 86% feeling tired
- 75% feeling stressed
- 69% disturbed sleep
- 55% feeling depressed
- 31% see GP for stress related illness

Control

- 70% of respondents said that they had some control over their life but not enough
- 11% said they had no control at all

Time outside of Caring

- 80% said they do things they enjoy but not enough
- Just 6% said that they don't do anything at all

Social Contact

- 49% said that they had some social contact but not enough
- 18% said that they had little social contact and feel totally isolated

Financial Situation

- 29% said they had financial problems to some extent
- And 11% said it was a lot.

Source: Adult Carers Survey 2019 Non-Statutory Summary Report (Data Requested by Carers Support West Sussex from West Sussex County Council)

3. Carer Strategy - Young Carer Engagement, (November 2020), West Sussex Young Carers

Overview

- The Young Carer Engagement Survey ran from 26/10/2020 to 08/11/2020
- Invitations to complete it were sent out to approx. 600 parent/guardian of YCs.
- 132 questionnaires were completed by young carers aged between 5 - 17 years (a return rate of 22%)

Key Findings

Top 3 challenges from highest to lowest % of responses:

- 70% Feelings of stress and worry
- 58% Managing your feelings
- 39% Your family not having enough money

Ranked most important by respondents:

- More support for myself, so I can feel stronger
- Raising awareness about young carers so what you are doing is recognised as soon as possible
- Increased funding for a break so I can take part in activities outside the house

Young Carers and School (selection of comments from survey respondents):

- *'There is a stigma attached to young carers. It's best not to talk about it in school at all otherwise you can get singled out more'*
- *'My teachers don't know because they would think I am too young'*
- *'I would like all my teachers to be aware plus the head as what I do is an important role'*
- *'I'd like to talk about how I'm feeling more'*
- *'Many of my friends do not understand what a young carer has to do at home or why it can upset me sometimes'*
- *'There aren't any posters or anything around school whereas other things are in almost every classroom'*

Young Carers and Impact of COVID-19 pandemic (132 responses collected for this question and main themes from responses summarised below):

- Negative impact of Covid-19 on the cared for and carer
- No break from caring role (feeling trapped)
- Increased worry/anxiety (feeling fearful)
- Behind with school work (lack of time, inadequate or no equipment, poor or no internet)
- Struggle to get back into school routine
- No one to talk to
- Not able to see wider family and friends
- Socially isolated and bored.

Source: Carers Strategy Young Carer Engagement Findings PowerPoint Summary (shared internally with stakeholders).

4. Research in Sussex Carers Experiences of Health Care, (March 2021), Sussex Carers Partnership

Overview

- Inclusion Engagement Project commissioned by the Sussex Clinical Commissioning Groups (CCGs)
- Research project delivered by the Sussex Carers Partnership, comprising of The Carers Centre for Brighton and Hove, Carers Support West Sussex, and Care for the Carers (East Sussex).
- Three carer discussion workshops hosted in January 2021, each with a main theme of discussion:
 1. Carers and Coronavirus: Planning for Recovery
 2. Caring Doesn't Come with a 'How To' Manual: Exploring Carer's Experiences of Navigating Healthcare Systems.
 3. The Invisible Army: Making carers visible
- Total of 22 carers participated in the workshops
- Supplemented with survey covering same themes (online and telephone). Total of 118 respondents.

Key Findings

Difficulty Navigating Healthcare Services

- Need proactive approach from healthcare providers
- Often a 'struggle' or a 'fight' to access care and support

Delayed/Cancelled Access to Healthcare Services

- Concerned by loss of regular checks and monitoring

Poor Carer Identification

- Carers not being recognised for their expertise
- Feeling 'left out'

Term 'Carer' Not Understood

- Difficult to self-identify as 'carer' - term does not resonate or negates relationships

Concerns Around Carer Contingency

- Lack of, or no, respite services during lockdown (i.e. day centres closed)

Impact on Carer Mental Health

- 80% of respondents in workshops cited negative impact of caring on mental health
- Includes loneliness and isolation and feeling invisible and anxious

Confusing Messaging About Covid-19

- Lack of consideration for carers who are also clinically vulnerable and carry out a caring role

Inconsistent Communication

- Communication between carers and healthcare providers seen as inconsistent
- Good communication dependent on individual/professional rather than a standard applied to all

7 Recommendations based on findings:

1. Incentives to Identify Carers

- Financial incentives for health services to identify carers
- Robust inclusion and engagement with Patient Participation Groups (via GP Practices)

2. Introduction of Mandatory Carer Awareness

- Mandatory carer awareness training for all healthcare staff
- Blended approach comprising of e-learning and face-to-face delivery

3. Centralised Carer Records

- Medical records with field for 'carer' prominent ('unknown' should not be an option)

4. Reduce Negative Impact of Caring on Mental Health

- Commissioning of resilience-building training for carers
- Mandatory mental health training for all healthcare staff

5. Regular and Consistent Messaging

- Utilise trusted sources (NHS, GP, Government) to cascade information to carers identified about annual vaccination programmes

6. Road Map for Services and Support

- Clear, concise and accessible recourse mapping out the services and support available.

Source:

<https://www.carerssupport.org.uk/assets/documents/Sussex.Carers.Partnership.Engagement.Report.pdf>

National

5. State of Caring: A snapshot of unpaid care in the UK, (2019), Carers UK

Overview

- Each year, Carers UK carries out a survey of carers across the UK to understand the state of caring
- 7,525 carers provided responses

Key Findings

- Women are more likely to take on a caring role (81% of the 7,525 carers surveyed identified as female and 18% as male).
- 24% of carers considered themselves to have a disability
- 2 in 5 carers surveyed were struggling to make ends meet (around 39%)
- 77% have had to cut back on hobbies and leisure activities
- 68% had to regularly use their own income/savings to pay for care or support services, equipment or products for the person they care for
- 4 in 5 carers (79%) reported using one or more types of technology
- Only 1 in 6 carers (17%) had had a conversation with an NHS professional (e.g. a GP or a nurse) about what to do if the condition of the person they care for deteriorates, or they are no longer able or willing to provide care for them
- Unpaid carers seven times more likely to be lonely compared with the general public (81% of carers reported feeling lonely or isolated as a result of their caring role).

Source:

http://www.carersuk.org/images/News_campaigns/CUK_State_of_Caring_2019_Report.pdf

Overview

- To coincide with Carers Week 2020 in June, Carers UK carried out polling with YouGov to revisit how many people were caring in the UK.

Key Findings

The polling found that:

- There are an estimated 13.6 million unpaid carers in the UK today
- 1 in 6 adults (17%) provide care and were already doing so before the coronavirus outbreak.
- 1 in 10 people (9%) only started caring since the coronavirus outbreak (equates to an additional 4.5 million unpaid carers)
- Combined figures suggest 1 in 4 adults provide unpaid care in the UK today

Carer Profile (before outbreak)	Carer Profile (since outbreak)
57% are women and 43% are men.	59% are women and 41% are men.
Nearly half (48%) are juggling paid work with their unpaid care. 34% are in full-time work and 15% are in part-time work.	Almost two thirds (62%) are in paid work – 41% are working full time, and 21% working part time.
4% are full time students.	6% are full time students.
A quarter (25%) are a parent or guardian for someone under 18. Many of them are sandwich carers; caring for an older, ill or disabled person while also being a parent or guardian of someone 18 or under.	35% are a parent or guardian for someone under 18, which is significantly higher than those who were caring already before the crisis.
23% are over 65, 23% are 55-64, 22% are 45-54, 16% are 35-44, 9% are 25-34, and 7% are 18-24.	14% are over 65, 17% are 55-64, 22% are 45-54, 21% are 35-44, 16% are 25-34, and 10% are 18-24.

The top three most frequently chosen challenges by all unpaid carers polled were:

- Managing the stress and responsibility (71%)
- The negative impacts on their physical and mental health (70%)
- Not being able to take time away from caring (66%).

These results closely matched what the public, who had never been unpaid carers, thought the challenges that unpaid carers face were:

- Not being able to take time away from caring (72%)
- Managing the stress and responsibility (70%)
- The negative impacts on their physical and mental health (69%).
- There were other important challenges that were frequently chosen by unpaid carers:
- The impact it has on other personal relationships (e.g. with family, friends, partners etc.) (63%)
- The negative impact it has on their ability to do paid work (55%)

- The financial impact of the additional care costs (e.g. specialist care equipment, home adaptations (53%)
- Not having anyone to talk to about the challenges of caring (50%).

The general public, who don't have a caring role, were asked what worries they would have if they took on an unpaid caring role. Their top three worries were:

- The negative impact on their own physical and mental health (56%)
- Not being able to cope financially, not being able to afford care services or equipment required (50%)
- Not knowing or understanding what help is available to carers (49%)

Source: <https://www.carersuk.org/for-professionals/policy/policy-library/carers-week-2020-research-report>

7. My Future, My Feelings, My Family, (July 2020), Carers Trust

Overview

- In June 2020, Carers Trust conducted a survey of young carers (aged 12 to 17) and young adult carers (aged 18 to 25) in the UK to find out how they have been impacted by Coronavirus.
- A total of 961 responses were collected.

Key Findings

Young Carers and Young Adults Carers say...	% of Young Carers (aged 12 to 17)	% of Young Adult Carers (aged 18 to 25)
their mental health is worse since coronavirus	40%	59%
they are more worried about the future since coronavirus	67%	78%
they are feeling more stressed since coronavirus	66%	74%
they are feeling less connected to others since coronavirus (both Young Carers and Young Adult Carers)	69%	
there has been an increase of 30 hours or more in the amount of time they spend caring per week	11%	19.7%

In summary, the Young Carers and Young Adult Carers wanted the following:

- Support for their emotional wellbeing and mental health
- Have breaks and respite from their caring role
- Get help from specialist young carers and young adult carers services
- Balance caring, so that they can succeed in education and employment
- Stay connected to friends and their communities
- Eat well and stay physically fit

Source: <https://carers.org/downloads/what-we-do-section/my-future-my-feelings-my-family.pdf>

8. GP Patient Survey Results: Carers, (August 2020), Carers Trust

Overview

- Independent survey run by Ipsos MORI on behalf of NHS England
- Survey is sent to over two million people across the UK

Key Findings

Compared to people not in a caring role, carers surveyed were more likely to:

- Report problems with physical mobility (15%)
- Feel isolated (9%)
- Take five or more medicines (21%)
- Have a long term physical or mental health condition (64%)
- Young Adult Carers are twice as likely as their non-carer peers to report feeling lonely and three times more likely to report problems with physical mobility.
- Older Carers (65+) have comparable health to their non-caring peers.

Trends for carers (all ages) 2018, 2019 and 2020

All Carers	2018	2019	2020	YAC* 2020
Reported problems with physical mobility	14%	15%	15%	9%
Feeling isolated from others	8%	8%	9%	26%
Take 5 or more medications on a regular basis	21%	21%	21%	7%
Long term physical or mental health conditions, disabilities or illnesses All ages: Arthritis (24%), a breathing condition (13%), diabetes (9%), high blood pressure (20%), and mental health condition (13%) YAC: Arthritis (6%), a breathing condition (13%), and mental health condition (26%)	62%	63%	64%	50%

*Young Adult Carers 16-24 years

	Hours spent caring					Patients not in a caring role
	1 - 9 hours	10 - 19 hours	20 - 34 hours	35 - 49 hours	50 hours +	
Reported problems with physical mobility	12%	15%	17%	19%	21%	12%
Feeling isolated from others	8%	9%	10%	13%	11%	7%
Take 5 or more medications on a regular basis	17%	20%	24%	26%	31%	18%
Long term physical or mental health conditions, disabilities or illnesses	60%	64%	65%	66%	72%	52%

- Table shows self-reported carer health outcomes across carers providing different levels of care per week.
- Results highlight the more care you provide, the more likely it is to impact your physical and mental wellbeing.

Source: Network Partner Briefing Summary by Carers Trust

Figure 1 - Hours Spent Carers (Carers Trust Briefing Paper, 2020)

9. Age and Digital Exclusion: A map of GP surgeries in England, (2020), Citizens Online

Overview

- Citizen Online conducted research into how many people use digital tools and services and how many are not online.
- 6,658 GP surgeries in England were mapped.

Key Findings

- Total of 25 GP surgeries were identified within the NHS West Sussex CCG border with less than 30% of patients online.
- Within the border, average % patients not registered for an online service was 76.95%.
- 25.81% of patients registered were aged 65+.

Table lists 24 GP surgeries with < 30 % patients online (within NHS West Sussex CCG border)

Total no. of patients: 259,100

Total No. of patients aged 65+: 66,885

Average % patients not registered for an online service: 76.95%

Total online transactions in April 2020: 29,323

Surgery	Total no. of Patients	No. of patients aged 65+	% patients not reg'd for an online service	Online transactions in April 2020
Arundel Surgery	6556	2098	89.72%	468
Avisford Medical Group	10771	3290	82.49%	1846
Ball Tree Surgery	14237	3625	74.86%	1676
Bersted Green Surgery	13591	2604	87.36%	720
Bognor Medical Centre	9059	1624	72.18%	575
Cathedral Medical Group	13956	2851	74.01%	1346
Coachmans Medical Practice	11023	1067	73.6%	1379
Crawley Down Health Centre	8324	1884	73.24%	1004
Fitzalan Medical Group	16106	3367	76.5%	1685
Flansham Park Health Centre	13348	4003	72.52%	1398
Glebe Surgery	12411	3844	71.48%	1155
Gossops Green Medical Centre	7513	1062	76.2%	785
Grove House Surgery	11653	4801	75.43%	3369
Harbour View Healthcare	14649	3444	71.56%	1351
Maywood Health Care Centre	15354	3062	71.87%	1926
New Pond Row Surgery	7924	1982	82.25%	242
Parklands Surgery	1043	2542	71.97%	1184
Riverbank Medical Centre	12583	3529	77.3%	1374
Rudgwick Medical Centre	3767	883	73.19%	624
Selsey Medical Practice	12505	4266	81.41%	1104
Steyning Health Centre	12164	3275	72.82%	1297
The Manor Practice	10465	2154	81.91%	776
The Orchard Surgery	6508	1518	84.06%	599
The Petworth Surgery	6032	1824	76.92%	549
West Meads Surgery	7558	2286	78.78%	891

Source: <https://www.citizenonline.org.uk/gp-map/>

LGBT / Minority Ethnic

10. The National LGBT Survey: Summary report, (February 2019), GOV.UK

Overview

- Over 108,000 people participated in a survey that was launched in July 2017, making it the largest national survey of LGBT people in the world to date.
- Results were published February 2019 and below are the key findings.

Key Findings

Feeling comfortable

- 56% of respondents felt comfortable being LGBT in the UK
- 19% of respondents had not been open about their sexual orientation or gender identity with any of their colleagues at the same or a lower level.
- 23% had experienced a negative or mixed reaction from others in the workplace due to being LGBT or being thought to be LGBT.

Safety

- LGBT people at greater risk than general population of being victims of crime (discrimination, hate crime, domestic violence)
- Stonewall found that 1 in 8 trans people had been attacked by a colleague or customer at work

Health

- LGBT people more dissatisfied by health services (includes lack of knowledge among medical staff about the health needs of LGBT people, specific concerns with mental and sexual health services and, among transgender people, concerns with the gender identity services provided by the NHS).
- Healthcare staff need training to not make heterosexual assumptions (i.e. if a gay male carer says 'my partner' the healthcare staff assume it's a woman and say 'she' in their response).

Accessing healthcare and disclosure

- Most (46%) LGBT people do not disclose/discuss their sexual orientation with healthcare staff either because it had no relevance or if it was shared, 75% say it had no effect (positive or negative).

Source: <https://www.gov.uk/government/publications/national-lgbt-survey-summary-report/national-lgbt-survey-summary-report>

11. “Hiding who I am”: The reality of end of life care for LGBT people, (2017), Marie Curie

Overview

- Report drew upon existing policy and research papers to identify the key issues experienced by Lesbian, Gay, Bisexual and Transgender (LGBT) people at the end of life.

Key findings

- Previous experience of discrimination meant LGBT people were concerned that they would not be treated with dignity and respect by health and care services.
- Their partners (carers) may not be entitled to be involved in decisions/discussion in the way they wish.
- Care Quality Commission (CQC) 2016 Report – [A Different Ending – Addressing Inequalities At The End Of Life](#) – found only 24% of CCG’s surveyed had undertaken and equality impact assessment for end of life services for groups with a protected characteristic.

Key Findings	What LGBT people say they need...
1. Anticipating discrimination – according to Stonewall, 3 in 5 older gay people are not confident social care/support services are able to understand and meet their needs.	Prefer social care services specially for LGBT people Able to access health and social care services run by LGBT people Images of LGBT people and symbols such as rainbow flag in promotional material makes them more comfortable to access services – need to feel acknowledged
2. Complexities of religion and LGBT end of life care – spiritual needs not addressed at end of life like any other patient/carer. Concerned that they will be treated with hostility by church-affiliated providers of hospice care.	Delivery of more holistic approach, which considers the whole person and what is important to them at end of life.
3. Assumptions about identity and family structure – being discriminated on the basis of sexual orientation.	Promotion of inclusive language – moving away from ‘what is normal’ - to help people disclose their sexual or gender identity Giving people the opportunity to self-identify
4. Varied support networks – concern that loved one will not be recognised or respected as next of kin; could be estranged from birth families so have alternative family structures in place, including constructed support (friends and support groups)	Advanced care planning Allow people to express preferences about care they wish to receive and who they would like to advocate on their behalf if they are unable to make their own decisions at later stage
5. Unsupported grief and bereavement – partners/carers feel isolated and unsupported during bereavement because of their sexuality.	More encouragement of open and honest discussions about who is important to the patient and exploration of any existing relationship dynamics This will help with identification of who needs support during bereavement

6. Increased pressure on LGBT carers – access to palliative care is late or not at all

Early signposting of carers for support by professionals involved
More formal support for end of life care at home, but assurances need to overcome concerns about having to hide their true identity if formal care is asked for at home.

Source: <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/june-2016/reality-end-of-life-care-lgbt-people.pdf>

12. LGBTQ & Caring, (August 2017), Carers UK

- Estimated that there are 390,000 LGBT carers in Britain
- LGBTQ may face additional challenges along their caring journey including discrimination and stigma.
- They may also feel that some services are ‘not for them’ or inclusive enough.
- Carers can also be pushed out or not entitled to be involved in the decision making/discussions about the person they care for, as explained by this carer:

“My partner’s family didn’t know we were a couple, even though I was her main carer. When we were with her family it led to tensions where we had to remember what we should and shouldn’t say or how to behave” – Norena, Carers UK

Source: <http://www.carersuk.org/files/section/5677/cuk-lgbtq-booklet-wales-final.pdf>

13. Half a Million Voices: Improving support for BAME carers, (March 2011), Carers UK

Overview

- In 2011, Carers UK surveyed Black, Asian and Minority Ethnic (BAME) Carers as part of their *Half a Million Voices* report

Key Findings

- There estimated to be around 500,000 Black, Asian and Minority Ethnic (BAME) carers in England (every year, 180,000 BAME people become carers)
- Indian carers are the largest BAME group (2.2% of all carers in England)
- Majority of BAME carers are of working age (9.74% of BAME carers in England juggle work and care)
- 1 in 5 BAME carers surveyed had given up work to care
- 52% of carers were providing round the clock care and were struggling financially
- BAME carers were more likely to be providing 20-49 hours of care per week (15% of all BAME carers) compared with White British carers (10%).
- BAME carers were more likely to be in poor health compared with White British carers (Indian, Black Caribbean and White Other communities show higher levels of poor health).
- 78% felt at the time that that reforms across health, social care and welfare would further exclude and exacerbate issues for BAME carers (including poverty and discrimination).

Source: <https://www.carersuk.org/for-professionals/policy/policy-library/half-a-million-voices-improving-support-for-bame-carers>

COVID-19

14. Caring Behind Closed Doors: Forgotten families in the coronavirus outbreak, (April 2020), Carers UK

Overview

- Online survey conducted by Carers UK between 3 April – 14 April 2020
- Total of 5,047 carers and former carers responded (4,830 carers and 217 former carers)

Key Findings

- Of the 5,047 carers surveyed, 82% identified as female and 18% as male
- 70% of carers were providing more care due to the coronavirus outbreak (on average, 10 additional hours of care a week)
- 55% of carers felt overwhelmed and were worried about carer burnout
- Type of care being provided also changed with 69% of all carers providing more emotional support, motivation and checking in with the person they care for over the phone or online
- 81% of carers reported an increase household spending, mainly on food
- 44% of carers reporting feeling 'lonely and cut off from people'
- Only 21% of carers were confident in having a contingency plan in place in case of an emergency
- 64% of carers had some significant problems in accessing food provisions
- 60% had significant issues in accessing cleaning or hygiene products.

Source:

https://www.carersuk.org/images/News_and_campaigns/Behind_Closed_Doors_2020/Caring_behind_closed_doors_April20_pages_web_final.pdf

15. Analysis of Covid-19 Public and Key Stakeholder Survey, (April 2020), Sussex NHS Clinical Commissioning Groups

Overview

- In April 2020, Sussex NHS Commissioner sought the views of people and communities to understand how people were coping during coronavirus (Covid-19).
- Around 2,000 responses were received from people in East Sussex (67%), West Sussex (21%) and Brighton and Hove (11%).
- Majority of respondents were over the age of 46 (83%) and identified as female (68%)
- 15% of respondents were carers (6% cared for their parent, 6% cared for a partner or spouse and 4% cared for another family member).

Key Findings

Responses were organised into 5 themes

Key Themes	Response Summary
1. Communication and messaging	<ul style="list-style-type: none"> • A lack of clarity, duplication and a lack of coordination • Lack of clarity on what to do if symptoms of Covid-19 were experienced. • A need to challenge the myths and misinformation on Covid-19. • Messages need to be in plain English, and available in alternative formats, and updated regularly.
2. Channels and types of communication	<ul style="list-style-type: none"> • Key channels of communication are national media, websites and through social media. • Local channels were also cited as important to a lesser degree.
3. Accessing NHS services for non Covid-19 related care	<ul style="list-style-type: none"> • Lack of clarity on how to access services for non Covid-19 related care, and a perception that some services were not available. • Concerns about accessing medical care (dental, hospital mental health etc.). • Concern about the impact on the NHS in future if people are not accessing the care they need now, or if this care is unavailable.
4. How people are coping	<ul style="list-style-type: none"> • Majority of respondents felt they were coping well, or fairly well. • Main area of concern was concern “family” (becoming unwell, or inability to see family members). • Other concerns were about mental wellbeing and worries about maintaining businesses. • Some reported challenges in accessing essential supplies, despite having accessed community support.
5. Community Support	<ul style="list-style-type: none"> • Most respondents indicated that they have not wanted or needed to access community support. • Those who had accessed support cited a large range of local support, including Parish Councils, VCS groups, online forums and informal local volunteers. • VCS organisations and social prescribers were mentioned as key sources of information and community support, and in reducing the risk of isolation.

Source: <https://www.westsussexccg.nhs.uk/wp-content/uploads/sites/4/2020/07/Analysis-of-Covid-19-Public-and-Key-Stakeholder-Survey-FINAL.pdf>

16. Beyond the data: Understanding the impact of COVID-19 on BAME groups, (June 2020), Public Health England (PHE)

Overview

- Literature review undertaken to identify if inequalities exist in how BAME groups are affected by COVID-19 infection when compared to the White British population.
- Stakeholder engagement also carried out with 17 sessions hosted by PHE involving over 4,000 people with a broad range of interests in BAME issues.

Key Findings

Data from PHE tells us people from BAME backgrounds are...	Anecdotal observations for some BAME communities during COVID-19 in Crawley*
More likely to be in public -facing, service-based occupations.	In Crawley, many families were reliant on Gatwick Airport and Manor Royal for jobs (occupations such as security guards, taxi drivers, luggage handlers, cleaners, sales and retails etc.). Most were on zero hour contracts or self-employed. Usually it would be the male members in the household who were earning. Carers from these communities would therefore benefit from financial support but likelihood that many are not aware of such financial support.
Over-represented in lower socio-economic groups and areas of deprivation.	Majority of the Mauritius / Chagossian Black community live in the deprived neighbourhoods of Crawley and likely to have experienced higher levels of food insecurity. More likely to live in overcrowded homes with multi-generational occupants. Within the Mauritius / Chagossian Black community, there are hidden carers supporting family members or friends as a result of drugs/alcohol misuse and/or mental health issues but most have been reluctant to make contact with formal services even when signposted to do so. Instead, they have been relying on smaller grassroot charities/church groups where little or no questions are asked when accessing support.
More likely to have co-morbidities.	Higher prevalence of type 2 diabetes in South Asian and African-Caribbean communities in West Sussex. Diabetes UK had done some local engagement work with the majority of the local places of worship in Crawley, which was well received. Yet to see if this work has resulted in an uptake of BAME people coming forward for health check-ups.
More likely to experience poor mental and physical health.	Previous engagement research (2015) into BAME communities in West Sussex found that most BAME individuals were dissatisfied with local with GP services. Therefore less likely to see their local GP about changes in their mental/physical health.

7 Recommendations based on findings:

1. Mandate comprehensive and quality ethnicity data collection and recording as part of routine NHS and social care data collection systems.
2. Support community participatory research to understand wider determinants of COVID-19 in BAME communities and develop programmes to reduce risk and improve health outcomes.

3. Improve access, experiences and outcomes of NHS, local government and integrated care systems commissioned services by BAME communities.
4. Accelerate the development of culturally competent occupational risk assessment tools that can be employed in a variety of occupational settings.
5. Fund, develop and implement culturally competent COVID-19 education and prevention campaigns, working in partnership with local BAME and faith communities.
6. Accelerate efforts to target culturally competent health promotion and disease prevention programmes for non-communicable diseases.
7. Ensure that COVID-19 recovery strategies actively reduce inequalities caused by the wider determinants of health to create long term sustainable change.

Source:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

17. Exploring the disparity of Covid-19 with the Crawley BAME Community, (September 2020), Citizens Advice

Overview

- Research funded by Sussex Partnership NHS Foundation and delivered by Citizens Advice into the experience of the Black, Asian and Minority Ethnic (BAME) community in Crawley, West Sussex.
- Engagement for this research took place as follows: 214 Surveys responses collected; 22 semi-structured interviews and 8 in-depth interviews carried out and three focus groups hosted.

Key Findings:

- 214 BAME respondents to the survey conducted by Citizens Advice Bureau (Asian 62%, Black 18%, Mixed 12 %, Other 8%)
- 60% of respondents were women
- 59% were homeowners
- Top 6 feelings due to COVID-19 were reported by respondents as follows: 46% felt anxious, 33% stressed, 26% angry or panicked, 44% reported mixed emotions, and 26% felt conflicted or confused.
- Crawley has seen the highest increase in the number of claimants (JSA or Universal Credit) between March – June 2020 (+3,220) highlighting economic impact on residents in the area.
- 74% of people surveyed accessed information from government briefings.
- Top 7 channels for preferred NHS communication were NHS website, Email, Text, Television, Social Media, Easy Read, and Letters.

7 Recommendations based on findings:

1. Ensuring the diversity of the BAME community is reflected in interventions so they work.
2. Organisations should create a “road map” with goals and timeframes to be shared and reviewed using quick local actions to demonstrate change.
3. Interventions and information must be accessible and equitable, tackling both language and communication barriers.
4. Work should be user led and informed by the needs and interests of the target audiences.
5. Developing and sharing the evidence base on downstream causes.
6. Early support with issues outside of health are needed to prevent widening health and social inequalities.
7. Lessons should be shared about how people connected, created structure and coped through lockdown.

Source: <https://www.advicewestsussex.org.uk/wp-content/uploads/2020/11/Citizens-Advice-in-West-Sussex-North-South-East-report-Exploring-the-disparity-of-Covid-19-with-the-Crawley-BAME-Community.pdf>

Primary Data Analysis

Primary data was collected through carer focus groups (in person and online) and through surveys (online and postal).

Focus Groups

Qualitative research was undertaken by attending two local carer groups in person between February – March 2020, before lockdown restrictions came into effect. After a postponed delay in response to the coronavirus pandemic, a further three carer focus groups were hosted online in September 2020. Total of 34 carers gave up their time to participate in these sessions.

Focus Group Date	Carers in attendance	Location
21/02/2020	5	Littlehampton
04/03/2020	4	Chichester
17/09/2020	9	Online (Zoom)
23/09/2020	8	Online (Zoom)
30/09/2020	8	Online (Zoom)

Further Carer Focus Groups scheduled for April 2021 to test recommendations as part of the Carer Engagement Strategy.

Surveys

The secondary data research and analysis aided in the design of the primary research (quantitative), which consisted of online and postal surveys.

- Survey 1: Carer Strategy Engagement – Stakeholder Survey (online), July 2020
- Survey 2: Carer Strategy Engagement – Carer Survey (online and postal), September 2020
- Online Poll: Carer Strategy Engagement – Testing Recommendations Poll (online), February 2021

A total of 34 carers took part in the Carer Focus Group meetings.

The table below presents the main points raised by carers about what was working well and not so well regarding carers' support.

<u>Working Well...</u>	<u>Not so well...</u>
<ol style="list-style-type: none"> 1. Attending the group is a good way to find information 2. Can form friendship through meeting other carers at the groups 3. Specific support groups based on caring roles 4. Helpful to have a direct line to support works for ongoing support outside of group meetings 5. Regular called from CSWS – described as a 'lifeline' 6. Carers Assessment which lead to a grant payment to spend on own wellbeing 7. Taking time out to de-stress (meditation has been helpful) 8. Age UK community navigators helpful in signposting for advice and information 9. Practical and emotional support being offered by family members was important in helping carers to continue caring. 10. Counselling service (accessed via GP) was very helpful. Provided a welcome replacement behind closed doors for informal chats and was viewed as a 'lifeline'. 11. Meeting professionals who were able to provide help and support that was relevant and acknowledged that carer was 'part of the solution'. 12. Maintain an informal reciprocal contact with other carers for peer support outside of groups (check in system for out of office hours). 13. Having a supportive employer who understands that flexibility is needed to manage caring responsibilities 14. Specialist support from CSWS (Macmillan) has been helpful 15. Cross Roads Care – respite service and options were helpful when accessed 	<ol style="list-style-type: none"> 1. Specialist groups – not so many and not always in location of carer 2. Calling Response Line and not being able to contact specific workers 3. Costs of phoning workers mobile 4. How do CSWS keep in contact with carers who do not use email? 5. Letting people know CS exists - discussion about where advertised, GP surgeries etc. 6. Large group – time to talk can be limited 7. Lack of bereavement support for carers 8. No information at the time about help for daughter as a young carer 9. Difficult to get through to support worker on the 0300 number so avoid calling. 10. Counselling offer in general (mention of Time to Talk service) within the area not been great when accessed via GP. 11. Not enough offer of social activities for carers (day trips or activities organised for carers would be appreciated, including during out of office hours for working carers. 12. Caring role not being recognised by employer 13. Feeling 'invisible' despite national awareness about carers 14. Financial hardship, especially due to loss of employment 15. Hidden disabilities – lack of understanding or compassion from others who do not see anything wrong with person and do not understand why care is needed 16. Need more than six sessions of counselling support 17. Due to lockdown and restrictions there have been little or no spontaneous opportunities to see other friends or peers.

<p>16. Support from carers groups – helpful to have a confidential space to off load without feeling ‘judged’</p>	<p>18. Transition between services can be difficult if you ‘don’t fit into the right box’.</p> <p>19. Constantly ‘fighting’ the system to get the support from services who should already be providing it – independent advocacy support needed</p> <p>20. Juggling caring role alongside day-to-day-tasks – need support that can ‘extend’ carers capability rather than replace the unpaid carer</p> <p>21. Lack of family carer approach (parent carers) limits choice and control over decisions</p> <p>22. Lack of advocacy support (carer and cared-for)</p> <p>23. Finding time to attend support groups for peer support – having groups outside of usual working hours</p> <p>24. Need more transparency from social/adults’ service around care packages</p> <p>25. Lack of suitable respite services/activities for cared-for who are aged 25+</p>
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Overview

- As part of the Carer Strategy Engagement, a survey was conducted with stakeholders.
- Total of 169 responses were collected between 6 – 30 July 2020.

Key Findings

- 40% of respondents in a caring role.
- 28% of all respondents worked for a Local Authority organisation.
- Top three referrals made to NHS or WSCC services were 1) Carers Health Team (25%), 2) Carers Emergency Alert Card Scheme (17%), and 3) Emergency Respite Service (16%).
- Top three onward referrals made to CSWS services were 1) Carers Support Group (20%), 2) Carers Assessment (15%), and 3) Carer Funds (12%).
- Two main methods of carer referrals were signposting for self-referral (34%) and email referral (25%).
- Top three issues identified as affecting All Carers were 1) Not being able to take time away from caring (23%), 2) Coping with the demands and responsibility of providing care (21%), and 3) Managing their own physical and mental health (15%).
- Top three issues identified as affecting Young Adult carers were 1) Missing out on socialising because of caring responsibilities (22%), 2) Juggling education alongside caring demands (18%), and 3) Not having anyone to talk to and feeling lonely (13%).
- Respondents said their organisation supported carers and caring well because 1) their activities recognise, value and support carers (19%), 2) they support carer health and wellbeing (19%), and 3) their strategy or action plan includes support for carers (17%).
- Respondents said their organisation could improve carer support and caring well by providing 1) Workforce training on carer issues and best practice (22%), 2) Clear measures to support staff who are juggling work and care, including consideration for paid care leave (22%), and 3) Better or systematic carer identification (17%).
- The most important of the Five Big Ideas for carers' support was 'Funding for carers' breaks needs to be increased so that more carers are able to access respite'. And the least important idea was 'A shared strategy or action plan that raises public awareness of carers and caring'.
- Future support services aimed at carers should take in account the following: Advocacy and carer rights; Affordable short break/respite options; Bereavement support & support after caring role ends; Emergency respite support; Identification of carers and communication about services; Joint up working, especially with GP's; Ongoing individual one-to-one support or co-ordinated support between agencies, and focus on Reaching rural carers.

Overview

- 1000 survey responses were collected between 17 August – 28 September 2020
- 915 online responses and 85 postal responses.

Research Findings

- 87% were carers, 7% former carers, and 6% potential carers
- 61% of respondents were not in paid employment
- 90% were providing care before COVID-19, 2% as a result of COVID-19, 2% took on a caring role as a result of COVID-19, and for remaining 8% the question was not relevant as they were not yet in a caring role.
- Respondents were more likely to support someone due to Old age and Frailty, Long-term Illness or Dementia or Memory Loss
- 68% of respondents live with the person/s they care-for

Challenges and Barriers

- Top three challenges respondents may have (or likely to have) experienced were Feelings of stress (19%), Managing their own physical and mental health (14%), and Not being able to take time away from caring (14%).
- Other challenges included:
 - Reluctance/resistance from cared-for person leaving some carers 'on the fringes' and confined as to what support they can offer;
 - Concerns about contingency planning;
 - Lack of joined up approach resulting in less timely support and offer of follow up appointments;
 - Welfare system described as being 'sluggish' and not transparent enough;
 - A 'inadequacy' of good quality day respite services;
 - Lack of collaborative working between services who work in a 'silo manner';
 - Not being able to see or visit cared-for (COVID-19 restrictions).
- Top three barriers to accessing help in a caring role were identified as Bureaucracy or paperwork (12%), Affordability of services (10%), and being Unable to leave cared-for (11%)
- Other barriers included:
 - 'Time caring takes' prevents access to help;
 - Lack of 'day care provisions' preventing carers from taking a break;
 - Broader support for end of life carers not available (only cancer support);
 - Lack of recognition as a carer in care home settings;
 - Feeling 'left completely in the dark' and 'cut out of' statutory care planning/care plan process;
 - Barrier in accessing face-to-face services if living in rural location;
 - Support services 'too fragmented' and not viewing the 'person and their situation as a whole';
 - Lack of clarity over eligibility of support and services.

Access to Services and Help

- 21% of respondents had not accessed any of the CSWS listed. However, for those who had - Carer Funds (15%), Carers Assessment (14%) and Carers Support Groups (13%) were most popular.
- 60% of respondents had not accessed any of the other NHS or WSCC services listed. However, for those who had - Carers Emergency Alert Card Scheme (16%), Carers Health Team (8%), Carer Short Breaks (3%) and Young Carers Service (age 0-16 years) were most popular.
- Majority of respondents (18%) had received no help that was most helpful to them, whilst others had found Equipment and/or home adaptations (13%), Financial Assistance (9%), and Having time for themselves (8%) helpful.
- Majority of respondents (37%) had received no help that was least helpful to them, whilst 22% felt that this question was not relevant to them. Comparable responses were recorded for the other all options with the following three options being popular – Support from GP (5%), Statutory carer assessment (4%), and Having caring role recognised in NHS setting (4%).
- The top priority for employers in the workplace to support carers was: Introducing flexible working to support working carers. Less of a priority was: Help line managers to empower carers.

Time out from Caring

- 38% of respondents would prefer to access a break away from caring without the person/s they care for, 27% both with and without cared-for, 15% with the cared-for, 12% were not sure/don't know, and 9% of respondents would not be able to take a break at all.
- The most helpful respite option would be A break away (respite holiday) (28%) followed by Homecare from a paid carer (16%) and then Getting friends and family to help (15%). Least popular option was A short stay in a care home (5%).

Communication and Information

- 43% of respondents do (or would) subscribe to email updates from CSWS in order to access content specific to their caring situation. The least popular option to subscribe would be to receive special offers (2%).
- Receiving too many emails would be the main reason why the majority (32%) of respondents would prefer not to subscribe to email updates from CSWS.
- Overwhelmingly, 84% of respondents do not need any training to get online with only 3% requiring training for complete beginners.
- Respondents prefer to receive information in the follow order of preference 1) Email, 2) Written Information, 3) Online (website of social media), 4) Face to face, and 5) Over the phone.
- 27% of respondents first heard about CSWS through a health professional, 19% don't know or were not sure, and 15% through word of mouth (friend or family).
- Other ways to have heard about CSWS were: Housing Association, GP Surgery, Day centre provider, Through work / Employer, Social Worker, Hospital / Health Professional, School, Event. Named organisations mentioned: WS Parent Carer Forum, Alzheimer's Society, WSCC, Citizens Advice Bureau, MIND, One You NHS website, Age UK.
- Least likely way to have heard about CSWS was Radio (0%).

Five Big Ideas

- Respondents ranked the Five Big Ideas in the following order of priority
 - 1) Reduce financial hardship as a result of providing unpaid care
 - 2) Improving identification of carers as expert partners in care in all NHS settings
 - 3) Funding for carers' breaks increased to provide more respite options
 - 4) Raising public awareness of carers and caring
 - 5) More support for carers to return to work alongside or after caring.

Monitoring Questions (optional)

- Respondents were aged Under 17 (0%), 18-24 (0%), 25-34 (2%), 35-44 (9%), 45-54 (21%), 55-64 (32%), 65-74 (19%), 75+ (14%), and 2% prefer not to say
- 80% identified as female and 18% as male and 2% prefer not to say
- 97% identified as the gender assigned at birth and 3% prefer not to say
- 87% identified as Heterosexual or straight, 7% preferred not to say, and 5% as LGBTQ and 1% prefer to self-describe.
- Overwhelmingly, respondents were White English (68%)
- 3% recorded as BAME
- 59% selected their religion or belief as Christianity, 15% none and 7% prefer not to say.
- 53% of respondents had no health problems or disability which had lasted or expected to last at least 12 months and that would impact their day-to-day activities significantly. However, for 26% of respondents' activities were limited a little, for 16% limited a lot, and 4% preferred not to say.
- 64% of respondents' relationship status was 'Married'.
- 98% were not currently pregnant or had been pregnant in the last 26 weeks.
- Regarding employment status, respondents were likely to be Retired (24%), Full-time Carer (22%), and in Full-time Employment (12%)
- 18% of respondents resided in Arun, 17% in Chichester, 16% Horsham, 15% Worthing, 13% Mid Sussex, 10% Adur, 9% Crawley, 2% Other, including Brighton, East Sussex, Surrey, Hampshire, Oxfordshire.
- 46% of respondents showed an interest in taking part in further follow up discussions.

Recommendations based on findings:

1. Carers to Be Identified, Involved and Valued
2. Greater Choice and Control to Help Maintain a Balanced Life and Care Well
3. Improved Social Opportunities for Young Carers
4. Independent Carer Advocacy Support
5. Carers to be Supported at Each Stage of the Caring Journey
6. Connecting Carers to Peer to Peer Support and Learning
7. Reducing the Financial Hardship
8. Inclusive Support for Seldom Heard Carer Communities
9. Support for Working Carers from Employers