BMJ Open

Identifying carers in general practice (STATUS QUO): a multicentre, cross-sectional study in England

Sarah Lawton [1,2] Christian Mallen,[2,3] Zarish Hussain,[4] Ram Bajpai [2]
Sara Muller,[2] Cath Holmstrom,[2] Clare Jinks,[2] Toby Helliwell[2,3]

To cite: Lawton S, Mallen C, Hussain Z, *et al*. Identifying carers in general practice (STATUS QUO): a multicentre, cross-sectional study in England. *BMJ Open* 2024;**14**:e083816. doi:10.1136/bmjopen-2023-083816

► Prepublication history for this paper is available online. To view these files, please visit the journal online (https://doi.org/10.1136/bmjopen-2023-083816).

Received 30 December 2023
Accepted 21 March 2024

Check for updates

© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

[1]Keele Clinical Trials Unit, Keele University, Keele, UK
[2]School of Medicine, Keele University, Keele, Staffordshire, UK
[3]Midlands Partnership NHS Foundation Trust, Stafford, UK
[4]Medical University of Bahrain, Adliya, Bahrain

Correspondence to
Sarah Lawton;
s.a.lawton@keele.ac.uk

ABSTRACT

Objectives To determine General Practice (GP) recording of carer status and the number of patients self-identifying as carers, while self-completing an automated check-in screen prior to a GP consultation.

Design A descriptive cross-sectional study.

Setting 11 GPs in the West Midlands, England. Recruitment commenced in September 2019 and concluded in January 2020.

Participants All patients aged 10 years and over, self-completing an automated check-in screen, were invited to participate during a 3-week recruitment period.

Primary and secondary outcome measures The current coding of carers at participating GPs and the number of patients identifying themselves as a carer were primary outcome measures. Secondary outcome measures included the number of responses attained from automated check-in screens as a research data collection tool and whether carers felt supported in their carer role.

Results 80.3% (n=9301) of patients self-completing an automated check-in screen participated in QUantifying the identification Of carers in general practice (STATUS QUO Study) (62.6% (n=5822) female, mean age 52.9 years (10–98 years, SD=20.3)). Prior to recruitment, the clinical code used to denote a carer was identified in 2.7% (n=2739) of medical records across the participating GPs. 10.1% (n=936) of participants identified themselves as a carer. They reported feeling supported with their own health and social care needs: always 19.3% (n=150), a lot of the time 13.2% (n=102), some of the time 40.8% (n=317) and never 26.7% (n=207).

Conclusions Many more participants self-identified as a carer than were recorded on participating GP lists. Improvements in the recording of the population's caring status need to be actioned, to ensure that supportive implementation strategies for carers are effectively received. Using automated check-in facilities for research continues to provide high participation rates.

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ A rapid recruitment and participation method to quickly update the caring status of consulting patients
- ⇒ Strong patient and public involvement and engagement input to inform the design and patient-facing documentation of the study
- ⇒ Inability to gauge the context of participant responses
- ⇒ The ability to collect only a limited amount of data from automated check-in screens

INTRODUCTION

In 2014, approximately 10% of the population were thought to be carers.[1] In 2018, it was estimated that there were around 7 million carers in the UK and that by 2030 the number of carers would increase by another 3.4 million people.[2] The most recent Census[14], together with Census data for Scotland and Northern Ireland, now suggests that there are 5.7 million adult carers across the UK. While these data indicate that approximately 9% of people are carers, Carers UK research conducted in 2022 estimated that the number of carers could already be as high as 10.6 million,[3] and the Health Foundation has recently reported a significant under-recording of carers in GP and local authority datasets.[4] The number of carers in the UK is not a static number but rather a dynamic estimate. All the time, caring responsibilities start for some and end for others, and so an estimate of the number of carers and who carers are needs to be regularly updated to ensure that needs are met.[5]

Unpaid carers provide an economically, socially and personally valuable service to the people they care for, estimated to cost £132 billion per year if provided formally. However, there is evidence that those providing care often neglect their own needs.[3] The National Carer's Strategy[2] reported that 71% of carers have had health problems which included poor physical and mental health. One of the main obstacles to carers getting the right support is being recognised as a carer—both through a process of self-identification and identification by health and care professionals. Relatively, few carers are formally acknowledged until a crisis occurs.[6] If carers frequently fail to recognise themselves as such, it will also be difficult for GPs and other health and social care professionals to identify them as carers.

The primary care team has a crucial role in identifying carers due to their established relationships with patients.[1] It is thought that better identification and recording of caring status will provide improved support to unpaid carers[7] and better care planning, with more efficient healthcare services.[4] Following identification of a carer and in line with Care Quality Commission guidance and good holistic practice, a coded term should be added to the carer's personal medical record (eg, 'is a carer'). Application of this code, however, is variable across general practices (GPs). Findings by MacMillan in 2019 suggested GPs have between 1% and 4% of their practice list size coded as carers, and in 2023, the Health Foundation reported recording to be between 1% and 11.5%.[4 8]

This study investigates GP recording of carers and the caring status of consulting patients, using automated check-in screens to collect brief data prior to a consultation.

METHODS

Design

The use of automated check-in screens to collect brief research data has been investigated by the research team elsewhere, also referred to as the 'AC DC methodology'.[9] Patients independently approach a check-in screen and touch the screen to select successively their sex and their day and month of birth. This then confirms the patient's arrival for their consultation. At this point, where available, some check-in screens have the facility to collect additional brief data from the patient, adding responses to the patient's medical record.

11 GPs within the National Institute for Health and Care Research (NIHR) Clinical Research Network: West Midlands (CRN: WM), whose GP Information Technology systems and services (GPIT Futures) were EMIS Health (formerly known as Egton Medical Information Systems) were invited to host the 'Quantifying the identification of carers in general practice Study' (or the 'STATUS QUO Study'). Participating GPs were required to have access to Egton Automated Arrival facilities, to include an automated arrival check-in screen and a Questionnaire Module.

Participants

During the 3-week recruitment period, all patients 10 years of age and older, who were attending for a booked appointment and completed an automated check-in screen to confirm their attendance for their appointment, were eligible to participate. Participant Information Leaflets were available next to the check-in screens. Once a patient had confirmed their attendance for a booked appointment, the research question(s) appeared on the screen for completion.

Consent

Regulatory approvals were obtained based on implied consent for anyone of age 10 years and older, due to the rapid way in which this study was conducted and in line with the definition outlined in Article 4 (11) of the General Data Protection Regulation guidance.[10] Participants were provided with up to 4 weeks a 'cooling off' period (before pseudonymised data were downloaded), should they wish to retract or amend their participation in the study.

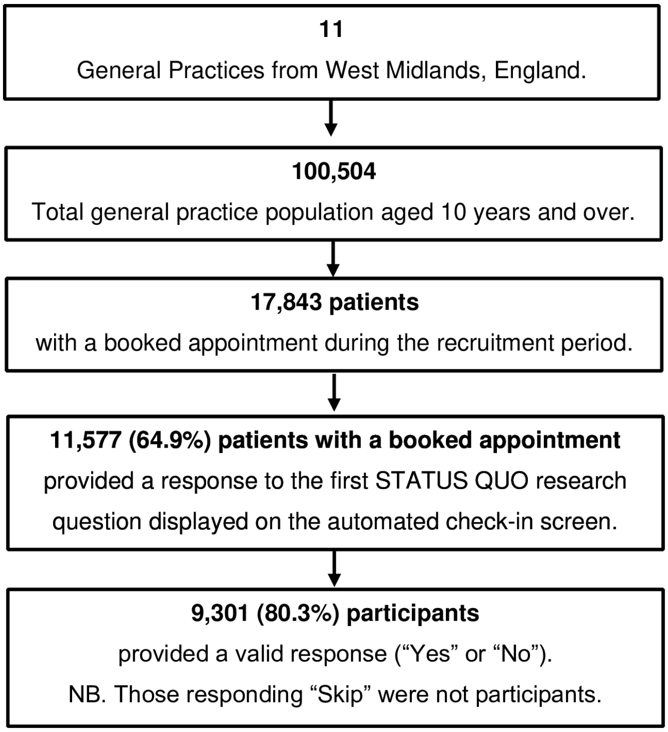
The inclusion of adolescent and adult participants in this study aged 10 years and over was supported by the North Staffordshire Carers (NSC) Association and determined by them, as an essential requirement.

Data collection

Participating practices collected data during a 3-week period, between September 2019 and January 2020. Two research questions appeared for completion once a patient confirmed their attendance for a booked appointment by using the practice check-in screen. The research questions included the following: 'Do you provide regular unpaid individual help and support for a friend or family member with a long-term illness, health problem or disability?', with responses 'Yes', 'No' or 'Skip', and for those identifying themselves as a carer (by responding 'Yes'), 'Do you feel you are supported with your own health and social care needs, in your role as a carer?', with responses 'Always', 'A lot of the time', 'Some of the time' or 'Never'. Responses were automatically filed back to patients' electronic medical record, inserting a clinical code to indicate that the person was a carer. A series of pseudonymised data extractions following recruitment were conducted by participating practices and securely transferred to the research team for analysis.

Patient and public involvement and engagement

The NSC Association helped to develop the STATUS QUO Study. The lead author (SAL) attended a NSC Support Group Meeting in April 2019 and worked with a group of 28 carers to review the study. Carers reviewed the proposed research questions to be displayed on the check-in screen, suggesting and agreeing on appropriate wording. The eligibility criteria for the study were also discussed and agreed. The group recognised that as soon as a person was mobile, even from the age of 2 years, they could become a carer. However, the group decided that eligibility for this study would be most appropriate from the age of 10 years. This age was agreed among the group of carers, to ensure comprehension of the research question being asked, in order to obtain reliable response data. The patient-facing documentation was discussed, in terms of content, layout, style and overall length. The wording of the STATUS QUO research questions, together with their associated options for completion, was agreed on by the group. It was also agreed that while recruiting for this study, alongside the study Participant Information Leaflet, access to additional carer support



11
General Practices from West Midlands, England.

100,504
Total general practice population aged 10 years and over.

17,843 patients
with a booked appointment during the recruitment period.

11,577 (64.9%) patients with a booked appointment
provided a response to the first STATUS QUO research question displayed on the automated check-in screen.

9,301 (80.3%) participants
provided a valid response (“Yes” or “No”).
NB. Those responding “Skip” were not participants.

Figure 1 Summary of STATUS QUO Study participants

information would be available. NSC provided a variety of resources and links for the research team to share with participating practices for display within the practice and on their websites.

Data analysis

Simple descriptive statistics were used to characterise the study sample and to compare potential demographic differences between responders and non-responders. T-tests and χ^2 tests were used to make comparisons between groups as appropriate. IBM SPSS Statistics V.24.0[11] was the statistical software used to analyse the data. In the production of and reporting on subgroups (practice, age group and sex), cell counts <5 were suppressed, and Office for National Statistics (ONS) guidance was followed on statistical microdata, to ensure the confidentiality of individual persons was protected.[12]

RESULTS

11 GPs, with a total population of 100 504 people, aged 10 years or over, hosted the study. Participating practice deprivation scores* ranged from 1 to 8, whereby a practice deprivation score of 1 is the most deprived and a deprivation score of 10 is the least deprived. The last practice completed data collection on 26 January 2020. There were 17 843 eligible participants with a booked appointment during the study recruitment period. 11 577 (64.9%) patients with a booked appointment provided a response to the first STATUS QUO research question displayed on the automated check-in screen. Of these, 9301 (80.3%) provided a valid response to the research question (figure 1).

STATUS QUO Study demographics is summarised in table 1.

The mean age of those with a booked appointment was higher than the mean age of those providing a valid response to the research question (55.5 years vs 52.9 years; p=0.001). The percentage of females providing a valid response to the research question was higher than the percentage of females with a booked appointment (62.6% vs 59.4%, p=0.001).

Practice coding of carers

Prior to the start of recruitment, the clinical term to denote a carer (Read code 918G) was identified in 2739 (2.7%) medical records across the 11 participating practices. The clinical term had been added in the last 3 years in 1949 (71.2%) cases.

STATUS QUO research question responses

11 577 patients answered the research question, ‘Do you provide regular unpaid individual help and support for a friend or family member with a long-term illness, health problem or disability’? The number of patients identifying themselves as a carer at each practice during the STATUS QUO Study recruitment period is displayed alongside the number of carers identified at each practice prior to recruitment, in table 2.

There was some variation by practice in the percentage of patients identifying themselves as a carer. The percentage identifying themselves as a carer from more deprived practices was higher than the percentage of patients identifying themselves as a carer from least deprived practices (10.9% vs 9.6%, p=0.035). More females identified themselves as carers than males (10.6% vs 9.2%, p=0.027), and those aged 50 years and over were more likely to identify themselves as carers than those aged between 10 years and 50 years. These observations were also reflected in the practice recording of carers.

Table 1 STATUS QUO Study demographics

	Age (years)		Sex (female)	
	Mean	**(SD)**	**N**	**(%)**
Demographics of those with a booked appointment n=17 843	55.5	(20.9)	10 604	(59.4%)
Demographics of those responding to the research question n=11 577	51.9	(20.5)	7138	(61.7%)
Demographics of those providing a valid response to the research question (participants) n=9301	52.9	(20.3)	5822	(62.6%)

Table 2 STATUS QUO Study carers and practice coded carers

STATUS QUO research question: 'Do you provide regular unpaid individual help and support for a friend or family member with a long-term illness, health problem or disability'? 'Yes'			**Percentage of practice list size ≥10 years coded as a carer, prior to STATUS QUO recruitment**	
Practice	**%**	**(n)**	**%**	**(n)**
1	15.7%	(27)	2.5%	(58)
2	10.0%	(125)	1.4%	(130)
3	8.5%	(15)	0.7%	(25)
4	10.0%	(114)	1.7%	(148)
5	7.7%	(66)	1.4%	(110)
6	9.3%	(104)	2.7%	(280)
7	10.9%	(90)	2.2%	(221)
8	9.6%	(75)	3.3%	(328)
9	10.1%	(120)	2.4%	(245)
10	10.6%	(84)	4.3%	(405)
11	11.6%	(116)	4.1%	(789)
Totals	**10.1%**	**(936)**	**2.7%**	**(2,739)**
Practice deprivation*				
≤5	10.9%	(362)	2.8%	(1,241)
>5	9.6%	(574)	2.6%	(1,498)
Totals	**10.1%**	**(936)**	**2.7%**	**(2,739)**
Age group				
10–17	5.2%	(22)	0.05%	(5)
18–34	5.5%	(93)	0.9%	(190)
35–49	11.0%	(199)	1.9%	(403)
50–64	14.3%	(315)	3.6%	(813)
65–79	9.0%	(216)	5.0%	(879)
80+	11.5%	(91)	6.5%	(449)
Totals	**10.1%**	**(936)**	**2.7%**	**(2,739)**
Sex				
Female	10.6%	(617)	3.6%	(1,821)
Male	9.2%	(319)	1.8%	(918)
Totals	**10.1%**	**(936)**	**2.7%**	**(2,739)**

*Deprivation was based on the 2019 English Index of Multiple Deprivation[13], using population-weighted GP deprivation scores, whereby a practice deprivation score of 1 is the most deprived and a deprivation score of 10 is the least deprived.

82.9% (776) of participants answered the research question about feeling supported with their own health and social care needs, in their role as a carer. Valid response options provided included the following: 'Always', 19.3% (150); 'A lot of the time', 13.2% (102); 'Some of the time', 40.8% (317); and 'Never' 19.3% (207).

DISCUSSION

This study has investigated GP recording of carers and the caring status of consulting patients. Of those patients attending their GP for an appointment, therefore eligible for this study, over a 3-week recruitment period, 65% provided a response to the STATUS QUO research question. 80.3% of these responses were a valid response (discounting 'Skip' responses), resulting in a total of 9301 participants recruited, while they were confirming attendance for a booked appointment, using the automated check-in screen. This result confirms response rate capabilities observed in a previous study conducted using automated check-in screens to collect brief research data or the AC DC methodology (85%).[9]

10.1% of participants in the STATUS QUO Study identified themselves as a carer. The STATUS QUO research findings concur with the existing literature,[8] estimating that 1 in 10 people identify as carers. Coding of carers by the GP, with the use of a term (eg, 'is a carer') inserted in the medical record, however, is presently lower than self-report (2.7%). The use of the AC DC methodology has provided a precise opportunity to collect data rapidly from a significant number of patients, while also updating their medical records by coding their caring status at the same time. Coding patients as carers where appropriate will help to ensure that their ongoing health and social care requirements are considered in future primary care contacts. In order for practices to update the caring status of their list, further data collection using digital methods such as text messages (SMS) is recommended, as the AC DC methodology works only for those who attend an appointment and check-in via the screen.

Females and those participants in the 50–64-year age range were most likely to identify themselves as a carer. These findings correlate with the Office for National Statistics Census data 2021, identifying that people aged 46–65 years were the largest age group of carers and that 59% of carers are women.[13] The NSC Association agreed that the research should capture responses from those aged 10 years or more, and 5.2% of those aged 10–17 years were identified as a carer. There may however be additional reasons why some children do not self-disclose being carers, either because they do not recognise this as a term or because of fears based on what the consequences may be.[14]

The variation by practice in the percentage of patients identifying themselves as a carer suggests that practice deprivation is a contributory factor, with more deprived practice populations reporting a higher number of carers. Variations may also be due to practice location (rural vs urban), or the nature of the carer support that is accessible, perhaps through specific clinician interest in this group of patients at the practice.

Impact of the COVID-19 pandemic

The emergence of COVID-19 in 2020 changed the responsibilities of many individuals. People took on additional caring responsibilities they might not have previously held, and as a result, the number of carers further increased. In April 2020, around one-third (32%) of adults were helping someone whom they did not help before the pandemic, and 33% also reported giving more help to people they helped previously.[13] While the number of carers is still higher than pre-pandemic, numbers have fallen since the height of the pandemic,[14] and estimates based on the results of the 2021 Census now predict that there are 10.6 million carers across the UK, translating to 1 in 5 adults holding caring responsibilities. This higher number however may be linked to a greater awareness of caring roles during the period in which the census was conducted, affecting identification.

Carers UK carried out an online survey between July and September 2022 to understand the state of caring in the UK.[15] This research highlighted that over a third of carers (36%) said that not knowing what services were available was a barrier to accessing support. 67.5% of STATUS QUO participants felt they were supported 'Some of the time' or 'Never' with their own health and social care needs. These findings further support a recommendation by Carers UK for primary care and local authorities to target carers when raising awareness about their services. This however can only be achieved where carers are known, and one of the main barriers to carers receiving the support they need is failure to self-identify as a carer. The Carers UK research found that half of all carers (51%) took over a year to recognise their caring role, with over a third (36%) taking more than 3 years to recognise themselves as a carer.

Strengths of the STATUS QUO Study

The use of the GP check-in screens to collect these brief research data on patients' caring status provided a cost-effective (where the technological infrastructure already existed), convenient and simple way to not only collect research data but also to update the medical record of those patients identifying themselves as a carer, without adding any further burden to the busy GP. The technology used to collect the study data enabled population-specific sampling and minimised sampling bias, and the entirely automated nature of the study ensured that delivery remained consistent. Further advantages included the following: the ability to monitor data collected in a live environment and the rapid resolution of any data collection problems; little disruption to practice operationalisation, providing an efficient way to embed research into a healthcare setting; and clinical coding to contribute to the pending consultation.

The strong PPIE input into the design of the study ensured that the presentation of the question to patients using the check-in screen was optimised and is likely to have improved the response rate and validity of the data collected. Future studies wishing to collect research data in this way should work with relevant patient groups to ensure suitable presentation of the questions and response options and to decide on patient eligibility to be shown the questions.

Limitations of the STATUS QUO Study

Using the AC DC methodology,[9] only a limited amount of data could be collected, with an inability to gauge the context of responses. Additional information about the caring demands of those identifying themselves as carers was therefore not possible.

While robust PPIE work was conducted with the NSC Association, in order to inform the design of the study and the wording for the definition of 'carer' used in the research question, we do not know whether the definition of 'carer' was interpreted as intended. The concordance between this study and national surveys in terms of the proportion of the population who are carers suggests a similar interpretation of the term to those studies. A markedly higher proportion of patients reported being a carer compared with those with a coded record of caring identified, indicating an under-recording in GP records compared with self-reported status.

Sampling biases are recognised, as only those GPs whose GPIT Futures was EMIS Health were able to participate. Within the practice, only those with a booked face-to-face appointment in the recruitment period and choosing to confirm their attendance for their booked appointment by using the check-in screen were eligible to take part. Those who checked in for their appointment with the receptionist may have needed to discuss other matters, had visual impairments and language barriers or were too unwell. They were not then provided the opportunity to participate. While a minority of patients registered with each practice were therefore eligible for the study, and there might have been some selection of this group by their ability to use the screen technology, a previous study using this methodology[9] has shown that those taking part had a similar age and gender distribution to people with booked appointments. Furthermore, the similarity of the estimate of carer status from this study to other self-report studies[3] gives confidence in the estimated proportion of people who are carers.

It could be seen as a limitation that it was not possible to compare individual self-reported caring status with records of caring status at the practice. However, given the large differences in these estimates, even without these individual-level data, it is possible to see that there are large discrepancies and that this and other digital methods (eg, SMS) are needed to ensure caring status is adequately recorded in GP.

In addition, it is known that carers are less likely to recognise their own ill health and therefore are less likely to consult than others who are similar but not carers. Identifying carers using the AC DC methodology therefore may need to be coupled with additional alternative methods of carer identification.

CONCLUSION

10.1% of STATUS QUO participants identified themselves as a carer. With a projected increase in the number of carers following the pandemic,[5] 'support for carers matters more than ever'.[16] Only 2.7% of those on the participating GP lists were identified as a carer, and 67.5% of STATUS QUO participants felt that their needs are supported, 'Some of the time' or 'Never'. Improvements are therefore needed to ensure that carers are identified and that supportive strategies are implemented. This will require exploration of how caring status can be shared with local authorities and those involved in the wider health and social care system to ensure carers gain access to the support they require.

Acknowledgements Thanks are expressed to the NSC Association and the 11 participating GPs within the National Institute for Health and Care Research (NIHR) Clinical Research Network: West Midlands (CRN: WM).

Contributors SL is the guarantor who accepts full responsibility for the finished work and the conduct of the study, had access to the data, and controlled the decision to publish. SL, CM, CJ, RB, SM and TH designed the study. SL collected the data. SL, ZH, RB and SM conducted the analysis. SL wrote the first draft of the manuscript. All authors contributed to subsequent drafts and read and approved the final manuscript.

Funding This work was supported by the Medical School, Keele University. CM, CJ, RB and SM are partly funded by the NIHR Applied Research Collaboration West Midlands (NIHR200165). CM is partly funded by the NIHR School for Primary Care Research (NIHR201784). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants, and the ethical approval was provided by the Yorkshire and the Humber - Leeds West Research Ethics Committee (19/YH/0260). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request. Keele University is a member of the UK Reproducibility Network and is committed to the principles of the UK Concordat on Open Research Data. The School of Medicine and Keele Clinical Trials Unit make data available to bona fide researchers upon reasonable request via open or restricted access through a strictly controlled access procedure. In the first instance, data requests and enquiries should be directed to medicine.datasharing@keele.ac.uk.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: http://creativecommons.org/licenses/by-nc/4.0/.

ORCID iDs

Sarah Lawton http://orcid.org/0000-0002-8909-2057
Ram Bajpai http://orcid.org/0000-0002-1227-2703

REFERENCES

1. Carduff E, Finucane A, Kendall M, *et al*. Understanding the barriers to identifying Carers of people with advanced illness in primary care: Triangulating three data sources. *BMC Fam Pract* 2014;15:48.
2. Department of Health & Social Care. Carers Action Plan 2018-2020 - Supporting Carers Today. London: Department of Health & Social Care, 2018.
3. Carers UK. Key facts and figures about caring. retrieved from Carers UK. 2022. Available: https://www.carersuk.org/policy-and-research/key-facts-and-figures/
4. Health Foundation. Can you tell we care?: identifying unpaid Carers using local authority and GP records. 2023. Available: https://www.health.org.uk/publications/long-reads/can-you-tell-we-care?utm_campaign=14204759_Can%20you%20tell%20we%20care%3F%20Unpaid%20carers%20long%20read%20%208%20Nov%202023%20%20WARM&utm_medium=email&utm_source=The%20Health%20Foundation&dm_i=4Y2,8GGGN
5. Petrillo M, Bennett M, Pryce G. Cycles of Caring: Transitions in and out of Unpaid Care. London: Carers UK, 2022.
6. Cameron J. How to identify and support Carers. retrieved from GP. 2012. Available: https://www.gponline.com/identify-support-carers/article/1143526
7. NHS Digital. Supporting Carers in General Practice: A Framework of Quality Markers. London: NHS England and NHS Improvement, 2019.
8. Macmillan. Gps and Carers: how can more Carers be identified. retrieved from MacMillan. 2019. Available: https://www.macmillan.org.uk/documents/getinvolved/campaigns/carers/gpsandcarers_summaryofsurveyandnextsteps.pdf
9. Lawton S, Mallen C, Muller S, *et al*. Investigating the usefulness of automated check-in data collection in general practice (AC DC study): a Multicentre, cross-sectional study in England. *BMJ Open* 2023;13:e062389.
10. Parliament E. Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing directive 95/46/EC (GDPR. *Official Journal of the European Union* 2016;1–119.
11. IBM CR. Ibm SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp, 2016.
12. Office for National Statistics regulation. Code of practice for Statistics edition 2.0. 2018.
13. Office for National Statistics (2020 July 9) retrieved from Coronavirus and the impact on caring. n.d. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/morepeoplehavebeenhelpingothersoutsidetheirhouseholdthroughthecoronaviruscovid19lockdown/2020-07-09
14. Carers UK. Make Caring Visible, Valued and Supported: Carers Week 2022 Report. London: Carers UK, 2022.
15. Carers UK. State of Caring 2022 - A Snapshot of Unpaid Care in the UK. London: Carers UK, 2022.
16. NHS England. Can you tell we care?: identifying unpaid Carers using local authority and GP records retrieved from health foundation. 2023. Available: https://www.england.nhs.uk/wp-content/uploads/2022/11/How-to-identify-and-support-unpaid-carers-October-2022.pdf
17. GOV.UK. English indices of deprivation 2019, 2019. Available: https://www.gov.uk/government/statistics/english-indices-of-deprivation-2019