Homecare
Association

Care Data Matters Consultation Response

Population, characteristics, needs and outcomes of people who draw on care and support including self-funders.

1. What information and data do people who use care and support services and their carers need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders?

Population Data

- Why it's needed: to understand the broader context of care recipients and to gauge the availability and demand for services in their area.
- Demographics of care recipients, e.g. age distribution - helps in finding age-specific support groups or services; gender ratio: useful for gender-specific services or support groups; ethnicity breakdown - helps in seeking culturally sensitive care.
- Geographical Distribution, e.g. urban vs. rural residents - provides insights into the accessibility and availability of services.
- Density of care recipients in certain areas: can indicate the demand and potential waiting times for services.

Characteristics of Care Recipients

- Why it's needed: to identify and relate to others with similar characteristics and to find specialised services.
- Health status: prevalence of specific health conditions - helps in seeking specialised care or support groups.
- Disabilities: useful for finding disability-specific services or aids.
- Mental health conditions: assists in seeking specialised mental health services.
- Lifestyle factors, e.g. smoking, alcohol, and substance use statistics - useful for those seeking cessation programmes or related support.
- Physical activity levels: helps in finding suitable physical therapy or exercise programmes.

Needs of Care Recipients

- Why it's needed: to understand the range of services available and to identify potential gaps in care.
- Type of Care Required: list of available services - helps users and carers choose the right service.
- Home-based vs. residential care statistics: provides insights into the most common care settings.
- Duration and frequency of care: average duration of care for specific conditions: Helps set expectations.
- Frequency of medical check-ups: useful for planning and scheduling.
- Support Systems: availability of family and friend caregiver support: Assists in planning for additional support.
- Community support groups: helps users and carers find peer support.

Outcomes for Care Recipients

- Why it's needed: to set expectations, evaluate the quality of care, and make informed choices.
- Health Outcomes: recovery rates for specific conditions: Helps set expectations and evaluate care quality.
- Complication rates: assists in evaluating the risks associated with certain treatments or services.
- Quality of Life Metrics: testimonials or case studies: provides insights into the holistic impact of services.
- Independence and autonomy statistics: helps evaluate the effectiveness of rehabilitative services.
- Feedback and satisfaction: client satisfaction surveys - assists in evaluating and choosing service providers.
- Complaints and grievances about providers: Helps users and carers make informed choices.

Information on Self-Funders

- Why it's needed: for those considering or currently self-funding their care, to understand the landscape and make informed financial decisions.
- Demographics of self-funders: statistics on who typically self-funds - helps in evaluating if self-funding is a common or viable option.
- Financial aspects: average costs of services - assists in financial planning.
- Insurance coverage options if applicable: helps in understanding potential financial support.
- Outcomes for self-funders: health outcomes compared to non-self-funders - assists in evaluating the benefits or drawbacks of self-funding.
- Satisfaction levels of self-funders: helps set expectations.

2. What information and data do care providers need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders?

Understanding the broader population that requires care and support in a specific geographic area (preferably Lower Level Super Output Area, LSOA) is crucial for analysing need now and in future. This informs the type of services required, the location of services, capacity planning, workforce development, resource allocation, service delivery, estimated costs of delivery, and level of investment required.

Population Data and Demographics

- Population density: number of people potentially requiring care and support services, their proximity to each other and to existing care services.
- Age: age-specific care needs can vary significantly.
- Gender: some health issues or care needs might be gender-specific.
- Ethnicity: cultural and ethnic backgrounds can influence care preferences and needs.
- Location: urban vs. rural settings might have different accessibility to care services.

Characteristics of Care Recipients

- To tailor care to individual needs, understanding the specific characteristics of those receiving care is essential.

Socioeconomic status, e.g.

- Income levels - can influence the ability to self-fund and the type of care sought. This may also affect the availability of workforce in an area.
- Employment status: might affect the availability of informal carers to support people, and also availability for care appointments or interventions.
- Education Level: can influence understanding and adherence to care plans.
- Cultural and linguistic background: to ensure culturally competent care and language barriers addressed.
- Living arrangements: to gauge whether they live alone, with family, etc., which can impact care strategies.

Health status, e.g.

- Chronic conditions: information on long-term health conditions like diabetes, heart disease, etc.
- Disabilities: physical, cognitive, or sensory disabilities that might require specialized care.
- Mental health: conditions like depression, anxiety, or more severe disorders.

Lifestyle factors, e.g.

- Diet and nutrition: dietary needs or restrictions.
- Physical activity: level of activity can influence care strategies.
- Substance use: information on tobacco, alcohol, or drug use.

Protected characteristics, e.g.

- Age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.

Needs of Care Recipients

- Identifying the specific needs of individuals ensures that care is person-led and effective.

Outcomes the individual desires, e.g.

- Independence: support to maintain as much independence as possible to preserve self-esteem and well-being.
- Safety: e.g. falls risk, needs for modifications to living space or obtaining mobility aids.
- Social connection: avoiding social isolation, connection to community and/or friends and family.
- Physical health maintenance: monitoring of health conditions, assistance in managing medications, attending medical appointments.
- Mental well-being: therapy or counselling options, engaging in activities to keep mind active.
- Activities of daily living: e.g. cooking, cleaning, shopping.
- Personal growth: goals and things the individual would like to achieve.
- Feedback and adaptation: assess changing needs, adjustments to care and support.

Type of care required

- Home-based care: for those who prefer or need care in their own homes.
- Extra care / housing with care: specialised housing with care and support.
- Residential care: for individuals who need 24/7 care in a facility.
- Specialised care: e.g. dementia care, palliative care, personal care, medication support, physical therapy, etc.

Engagement with other services

- Information about the person’s previous and concurrent care providers, to ensure co-ordinated care.
- Information about the person’s hospital admissions and discharges – to anticipate and plan for pre- or post-hospital care.

Support systems

- Family and friends: their involvement and capacity to support.
- Community resources: available local resources or services.

Level of dependence

- Ranges from fully independent to needing full-time care.

Frequency and duration of care

- Daily visits, weekly visits, overnight care, live-in care etc.

Preferred time of service

- Some may prefer morning visits, others evening.

Digital preferences

- Willingness and ability to use digital solutions and care technology.

Outcomes and Feedback

- To continually improve care quality, providers need data on the outcomes of their services and feedback from those they serve.

Improvement metrics

- Track the progress in health or well-being over time, e.g. recovery rates - how many individuals recover or improve after receiving care.
- Complications - any negative health outcomes resulting from care.

Goal achievement

- How effectively the individual goals of people drawing on services are being met.

Satisfaction and feedback

- Surveys and reviews: feedback on the quality and effectiveness of care.
- Complaints: areas where care might be lacking or problematic.

Incident reports

- Any accidents, incidents, safeguarding concerns, or deteriorations in health.

Information on Self-funders

- For those who fund their own care, understanding their specific situations and preferences is crucial. In addition to the points above, which apply to everyone, information is needed on:

Financial assessments

- To understand their capacity to pay without external funding.
- Preferred payment methods: direct debit, online payment, cheques etc.
- Billing cycles: monthly, quarterly, or annual payments.

Additional services opted for

- Any special services chosen that might be beyond the standard care package.

A common concern when it comes to any government body collecting and holding data on social care from providers is that the aggregate data is often not made available to the care providers who input the raw data. This can limit providers' ability to undertake analysis and plan service developments that will meet the needs of the local population. One suggestion would, therefore, be for national bodies to facilitate the operation of data sharing portals where social care providers can access the key statistical data that their ICS(s) hold on social care provision. This would support the government's objective of improving integration across the sector.

It is also important that innovations and best practice within the sector are tracked, examining the outcomes of the people that draw on care and support services to encourage best practice across the sector.

3. What information and data does Local Government (including local authorities and their staff) need, in relation to population, characteristics, needs an outcomes of people who draw on care and support including self-funders?

Local governments play a pivotal role in planning, funding, and overseeing care and support services for their communities. They need a comprehensive set of data to ensure that these services meet the needs of their populations, including those who are self-funders, e.g.

Population data

- Total Population: essential for resource allocation and planning.
- Demographic breakdown: age groups, gender distribution, ethnic backgrounds, socio-economic status.
- Migration Patterns: inflows and outflows of people which can affect demand.
- Number of people needing care and support services.
- Number of people drawing on care and support services.
- Demographic predictions - projected age distribution, population growth rates, potential influx of residents.

Characteristics of people drawing on care services

- Socioeconomic Status: helps identify those who might need financial assistance or subsidies.
- Cultural and Linguistic Diversity: ensures services are inclusive and accessible to all.
- Education and Employment Status: can influence health outcomes and care needs.
- Housing Situation: understands how many live in private homes, care facilities, homeless shelters, etc.

Needs of people drawing on care services

- Type and Severity of Disabilities: to cater to specific needs, be it physical, cognitive, or sensory.
- Chronic Health Conditions: information on prevalent conditions like diabetes, heart disease, mental health disorders, etc.
- Social Support Needs: identifying those who might need companionship services, respite care, etc.
- Previous care placements, hospital admissions, length of service use.

Outcomes data

- Service Utilisation Rates: how often people access care services and which services are most in demand.
- Feedback and Satisfaction: understanding user satisfaction to improve service quality.
- Health and Well-being Metrics: track overall health outcomes, recovery rates, and more.
- Safety and Incident Reports: monitoring the safety and quality of care environments.

Data for Self-funders

- Number and Demographics: how many people fund their care privately and their characteristics.
- Types of Services Chosen: understanding which services self-funders prioritise.
- Expenditure Patterns: how much they spend and on what services.

Service Availability and Capacity

- Number of residential care facilities, e.g. nursing homes, extra care housing
- Homecare providers: number and location of agencies providing in-home care; registered vs unregistered services; provision for self-funded vs state-funded people.
- Service wait times: time taken from requesting a service to its provision.
- Level of unmet need and its consequences.

Financial Data:

- Government Expenditure: how much is spent on care and support services.
- Funding Sources: breakdown of local funds, central government grants, etc.
- Direct payments vs managed funds.
- Allocated vs. spent budgets.
- Anticipated future budgets.

Contracts, Partnerships and Collaboration:

- Independent Providers: details on contract types, contract performance, costs.
- NGOs and Charities: collaboration with voluntary sector organisations that provide or augment care and support.

The lack of comprehensive and standardised data surrounding self-funders prevents effective support and improving outcomes for people in social care. Data collected on the size of the self-funded care population and their different routes they use to fund their care is needed. Without it, local government will struggle to manage the local market and to understand if there is sufficient care to meet demand.

Too little information is known about how a large portion of the market fund their care, and local authorities do not always have a good awareness of the providers offering self-funded care in their area. In order to effectively communicate with homecare providers local authorities should have an accurate picture of all of the providers operating in their area.

Furthermore, what challenges are those who do not meet the thresholds for local authority funded care facing? Given the need for public financial planning in today's economic climate, information on those who are, or soon will, become eligible for local authority care due to the depletion of funds will provide helpful intel on the increase in demand and increased cost facing the Government in the near future.

There is currently insufficient data to identify the level of unmet need in social care among working age disabled adults. This would help to identify a true representation of national and local need for adult social care so that, for example, resources could be allocated more accurately and help to prevent unmet needs from increasing.

4. What information and data does National Government need, in relation to population, characteristics, needs and outcomes of people who draw on care and support including self-funders?

National government needs to aggregate, analyse, and act on data to develop policies, allocate funds, and ensure that care and support systems across the country are efficient and effective. Data and information they might require includes:

Population Data:

- Total Population: essential for overall resource allocation and policy planning.
- Demographic Breakdown: age, gender, ethnicity, etc. to anticipate varying needs across population subsets.
- Population Growth Projections: to forecast future care and support needs.

Characteristics of People Drawing on Services:

- Socioeconomic Distribution: understanding the economic diversity to tailor support mechanisms.
- Regional Distribution: identifying which regions have the highest concentration of service users.
- Occupation and Employment Status: employment can influence health and support needs, as well as the ability to self-fund.
- Housing and Living Arrangements: identifying the living conditions of those needing care, from private homes to institutional settings.

Needs of Service Users:

- Prevalent Health Conditions: gathering national data on conditions like dementia, cardiovascular diseases, mental health disorders, etc.
- Care Dependency Levels: how many require full-time care vs. occasional support.
- Specialised Care Needs: identifying specific care niches, such as older people, disabled people under 65, palliative care, paediatric care, etc.
- Unmet need and consequences.

Outcomes Data:

- Service Utilisation: data on national trends of how and when people access care services.
- Recovery and Improvement Rates: to gauge the efficacy of care systems.
- Patient and Service User Feedback: national surveys to monitor satisfaction and areas of improvement.
- Safety and Incident Metrics: ensuring national standards for safety and quality are met.

Data on Self-funders:

- Number and Demographics: getting a national perspective on how many people fund their own care.
- Expenditure Trends: understanding how much self-funders spend, on average, and which services they prioritise.
- Financial Challenges: recognising if self-funders face financial hardships and how this affects their access to care.

National Infrastructure Data:

- Total Care Facilities and Services: understanding capacity across the country for state-funded and self-funded people

- Regional Variations in Care Providers: identifying areas with limited or excessive services.
- Rural vs. Urban Service Availability: recognising disparities and planning accordingly.
- Environmental impact of care services and mitigations.

Financial Data:

- National Expenditure on Care and Support: how much of the national budget is allocated.
- Source Breakdown: how much comes from national taxes, local taxes, grants, insurance etc.
- Economic Impact Studies: understanding the broader economic implications of care and support systems.

Regulation and Compliance Data:

- Registered vs unregistered services: ensuring all care providers meet national standards.
- Quality and Compliance Reports: monitoring and addressing lapses in quality, compliance or safety.

Research and Innovation:

- Investment in research, innovation and technology in care and support services.
- Outcomes of academic and industrial research on care and support.
- Evidence base for understanding which methods or interventions have the best outcomes.
- Technological Integration: monitoring the adoption of technology in care provision and its impacts.

Quality of care and support (including early intervention, safeguarding and integration of health and care services)

5. What information and data do people who use care and support services and their carers need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?

For individuals relying on social care services and their unpaid carers, accessing the right data and information is pivotal. This ensures that care is not only timely but also tailored to the unique needs of the individual.

Early Intervention

- Early intervention in social care can prevent or mitigate complications, ensuring that individuals receive the right support at the right time and to ensure resources are effectively allocated.
- Service users and carers need to know they are entitled to needs assessments and financial assessments and how to go about obtaining help.
- They need to understand their rights under relevant legislation, e.g. Care Act 2014 and what to do if they feel these rights have been breached.
- They need to know they may be entitled to advocacy help.
- They need to understand costs.

Innovation

- Service users need to know what new services and technologies are available to support them and how to access them.

Safeguarding

- Service users and carers need to be protected from harm.
- They need to know their careworkers have been well-trained and that services are of good quality, e.g. information on the qualifications, training, and background of social care providers.
- They need to know how to report concerns and who to escalate concerns to if they are not dealt with adequately.
- Independent reviews of services, both positive and negative. Direct insights from service users and carers about any concerns or areas of discomfort.

Integration of Health and Social Care Services

- Information on how social care interacts with health services, and vice versa.
- Shared Care Records: comprehensive records that can be accessed by the individuals, their carers and health and social care providers.
- Insights from service users and carers on the effectiveness and challenges of integrated services.
- Named professionals who can help them navigate the health and care system.

6. What information and data do care providers need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?

Social care providers must ensure that the care that they deliver is of the highest standard. The quality of care encompasses various elements, from early interventions to the integration of health and care services.

Early Intervention

- Data which helps to identify and address potential issues before they escalate, e.g. ability to perform activities of daily living; behaviour and mood changes; social circumstances such as relationships, communications, state of property; monitoring health signs.
- Data on risk factors: helps in predicting and preventing more severe problems, e.g. family history, early signs of cognitive decline, recurrent minor health issues, frailty scores, multi-morbidity, falls risk.
- Service user feedback: individuals might identify minor issues or challenges that can be addressed promptly, e.g. via surveys, feedback forms, direct communication, remote monitoring devices.
- Monitoring and surveillance Data: continuous monitoring can detect early signs of deterioration or need, e.g. health vitals, mood charts, mobility levels.

Innovation

- Data to guide implementation of new methods or technologies to improve care delivery.
- Research and study outcomes: understand the latest in care research and potential improvements, e.g. clinical trials, academic research papers, pilot study results.
- Service or technology adoption rates and feedback: gauge how well new services or technologies are being adopted and their efficacy, e.g. usage statistics, user feedback on new services or technologies.
- Cost-benefit analyses: ensure that innovations are economically viable, e.g. ROI calculations, long-term financial projections.

Safeguarding

- Data to protect vulnerable individuals from harm or abuse.
- Incident reports: track any incidents of abuse, neglect, or other harm, e.g. documentation of incidents, witness statements, photographs.
- Training and certification records of staff: ensure all staff are trained in safeguarding protocols, e.g. training completion certificates, refresher course dates, competency assessments.
- Background checks for safer recruitment: ensure that those working with vulnerable individuals are trustworthy, e.g. criminal record checks, reference checks.

Integration of Health and Care Services

- Data to facilitate seamless collaboration between health and care providers for holistic care.

- Shared health records: provides a comprehensive view of a user's health and care needs, e.g. electronic care and health records, medication logs, treatment plans.
- Communication logs between providers: monitor the frequency and quality of inter-provider communication, e.g. email correspondence, meeting minutes, collaborative care plans.
- User experience surveys to understand the user's experience with integrated care, e.g. surveys about transition experiences, feedback on coordination, testimonials.

7. What information and data does local government (including /local authorities and their staff) need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?

Local governments play a crucial role in overseeing, funding, and ensuring that care and support services within their jurisdiction meet the required standards. To achieve this, they need to focus on various elements, including:

Early Intervention

- Data to address proactively issues at the initial stages to prevent escalation.
- Community Health Profiles: identify areas or demographics at higher risk, e.g. health statistics, social determinant data, environmental factors.
- Feedback from Healthwatch, social care providers, charities and voluntary organisations: frontline providers can offer insights into emerging issues, e.g. reports on frequent health concerns, common challenges faced by users.
- Local school and educational data: early signs of social or health issues often manifest in educational settings, e.g. school attendance records, reports of behavioural issues, special education needs.

Innovation

- Data to evidence value of adopting and supporting new methodologies or technologies to improve care.
- Local Research Collaborations: partner with local institutions to drive innovation, e.g. joint projects with universities, pilot programs, local research initiatives.
- Feedback on new service or technology implementation - understand how new service or technology solutions are received and any challenges faced, e.g. feedback forms from care providers, usage stats, reported service or tech-related issues.
- Grant and funding data: allocate resources to promising innovative projects, e.g. proposals, outcomes of funded projects, ROI data.

Safeguarding

- Data and information on safeguarding referrals and outcomes.
- Information on outcomes of serious case reviews.
- Evidence of learning and improvement from safeguarding incidents.
- Local crime and incident Reports: monitor and respond to incidents affecting vulnerable individuals, e.g. police reports, hotline data, whistleblowing incidents.
- Training programmes and compliance: ensure local care providers follow safeguarding protocols, e.g. training session records, certification renewals, non-compliance reports.
- Public awareness campaign data: raise community awareness about safeguarding, e.g. campaign reach, community feedback, engagement metrics.

Integration of Health and Care Services

- Data to facilitate efficient collaboration between various health and care providers.
- Inter-agency communication records: track how well different agencies collaborate, e.g. meeting records, shared planning documents, inter-agency agreements.
- User experience and transition data: ensure that users experience seamless transitions between services, e.g. patient feedback after hospital discharge, testimonials, surveys on integrated care experiences.
- Service accessibility metrics: monitor how accessible integrated services are to the public, e.g. wait times for services, distance/travel data to access services, service utilisation rates.

8. What information and data does national government need, in relation to quality of care and support (including early intervention, safeguarding and integration of health and care services)?

At a national level, government plays an oversight role, establishing standards, allocating funds, and monitoring the overall health and well-being of the population. To ensure the quality of care and support services across the country, the following data and information are crucial.

Early Intervention

- Data to enable the prioritisation of prevention and address issues before they escalate on a broader scale.
- National Health and Welfare Surveys: obtain a snapshot of the nation's health and social well-being, e.g. national health statistics, prevalent health conditions, at-risk demographics.

- Feedback from local authorities: local government can offer granular insights into specific community needs, e.g. reports on regional health challenges, local intervention successes or failures.
- National Screening Programme Data: early detection of conditions can lead to more effective interventions, e.g. participation rates, findings from screenings, follow-up action rates.

Innovation

- Data to help champion and support advancements in care methodologies and technologies.
- National Research Databases: centralise and assess research initiatives to identify promising advancements, e.g. registry of clinical trials, research outcomes, innovation hubs.
- Technology adoption metrics: gauge how quickly and effectively new solutions are being integrated, e.g. national metrics on tech usage in care, feedback on tech-driven care solutions.
- Innovation funding data: allocate and monitor funds designated for innovative projects, e.g. grants or contracts awarded, performance metrics of funded projects, innovation ROI.

Safeguarding

- National Safeguarding Incident Database: consolidate and monitor incidents to detect patterns or systemic issues, e.g. reports of abuse or neglect, patterns of incidents, response metrics.
- Regulation and Compliance Data: maintain national standards and ensure adherence, e.g. regulatory inspection reports, compliance ratings, penalties or actions taken.
- Public awareness and education metrics: national campaigns to elevate awareness and understanding of safeguarding, e.g. campaign reach, feedback from the public, changes in reporting rates post-campaign.

Integration of Health and Care Services

- Data to facilitate cohesive and efficient care across health and social care services.
- Inter-departmental coordination records: monitor collaboration between national health and social care departments, e.g. joint initiatives, shared funding models, collaborative policy-making.
- Data on care pathways: ensure users can transition seamlessly between services, e.g. patient journey maps, feedback on integrated care experiences, gaps in service pathways.
- Infrastructure and access metrics: evaluate the national landscape of service availability and accessibility, e.g. distribution of care facilities, regional disparities, wait times for services.

Supply of Care Services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)

9. What information and data do care providers need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)?

Supply of Care Services

- Service availability: to ensure adequate coverage and reach of services, e.g. number of service providers, geographical coverage, types of services offered.
- Service utilisation: assessing demand and aligning resources accordingly, e.g. number of users per service, frequency of service use, service duration.
- Waiting Lists: addressing service bottlenecks and managing demand, e.g. number of individuals waiting, wait time durations, reasons for the wait.

Local Authority Commissioning

- Commissioned services details: keeping track of contracted obligations and performance indicators, e.g. service details, contract terms, performance metrics, payment terms.
- Feedback from Local Authorities: continuous improvement and ensuring contract adherence, e.g. performance reviews, areas of concern, feedback on service delivery.
- Service user profiles: tailoring services to meet the unique needs of the population, e.g. age, health conditions, specific care needs, duration of service use.

Accountability and Quality Assurance

- Incident and Complaint Reports: addressing issues promptly and improving service quality, e.g. nature of incidents, resolution steps, follow-up actions, user feedback.
- Audits and inspections: ensuring adherence to standards and regulatory compliance, e.g. audit dates, findings, recommendations, action plans.
- Outcome and satisfaction metrics: evaluating service impact and user satisfaction, e.g. service user feedback, outcome measurements, quality of life indicators.

Market Dynamics

- Occupancy and capacity: efficient resource management and anticipating service demands, e.g. total capacity, current occupancy rates, turnover rates.
- Discharge information: understanding service exit patterns and refining care pathways, e.g. reasons for discharge, post-discharge destinations, length of stay.
- Competitor analysis: staying competitive and understanding market trends, e.g. services offered by competitors, pricing structures, unique selling propositions.

10. What information and data does Local Government (including local authorities and their staff) need, in relation to the supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)

Supply of Care Services

- Objective: ensure adequate provision of care services to meet the needs of the local population.
- Demand forecasting data: predict the future requirements for care services based on population growth, aging demographics, and other factors, e.g. population projections, health trend analyses, local census data.
- Current capacity metrics: understand the current ability to serve the community's needs, e.g. number of care beds available, staffing levels across all care settings, waiting times for services; unmet need.
- Service utilisation rates: gauge how frequently current services are being utilised, e.g. bed occupancy rates, appointment bookings, home care service requests, number of homecare visits, number of people supported, average visit length, average travel time between visits.
- Workforce statistics.

Local Authority Commissioning

- Objective: facilitate the procurement of care services that meet the quality and capacity needs of the community.
- Quality metrics of potential service providers: ensure commissioned services meet desired standards, e.g. past performance reviews, client feedback, inspection results.
- Budget and cost data: align commissioning decisions with available funds, e.g. cost breakdowns, historical spending data, projected budgets.
- Contract performance metrics: evaluate the performance of different contract types in the short and longer-term; e.g. block contracts vs spot contracts; zero-hours vs guaranteed hours contracts; frameworks vs preferred providers; complexity of need, fee rates and visit length vs

outcomes, quality ratings, staff retention; unmet need, inability to place care packages and why.
- Monitor the performance of commissioned providers, e.g. number of people supported, service delivery timelines, adherence to contract terms, outcomes for people drawing on services, staff turnover, service continuity.
- Data on contracts handed back and reasons for this, e.g. financially unviable, travel time too long in rural areas, inability to recruit and retain staff.

Accountability

- Objective: ensure transparency, adherence to standards, and rectify any shortcomings in service provision.
- Incident and complaint reports: identify areas of concern and address them promptly, e.g. complaints from people drawing on services, incident logs, whistleblower reports.
- Audit and inspection findings: ensure ongoing compliance with standards and regulations, e.g. health and safety inspections, quality of care audits, financial audits.
- Feedback and satisfaction surveys: understand the community's perception of the care services provided, e.g. satisfaction surveys, caregiver feedback, public opinion polls.

Markets (including occupancy, capacity, and discharge)

- Objective: monitor the health of the care service market to ensure sustainability and quality.
- Market entry and exit data: understand the dynamics of service providers entering or leaving the local market, e.g. new facility registrations, closures of care homes, mergers/acquisitions, new registrations of homecare and other services, number of dormant services.
- Capacity and occupancy metrics: evaluate the availability and utilisation of care facilities, e.g. number of available beds, percentage of occupied beds, waiting lists, staff vacancy rates.
- Discharge data: monitor the transition of people from one care setting to another, e.g. average length of stay, delayed discharges with reasons, successful home transitions, readmission rates.

The integration of health and care services is paramount if the sector is going to meet the rising increase in demand. Key indicators around effective joint working between health and social care could include data on delayed transfers of care, hospital readmission and prevention of escalation of need. The reason that people are delayed at discharge, including if they are waiting for care, should be collected and broken down by service.

Furthermore, the feedback from people using services, waiting times, fee rates paid and commissioning practices should be compared between Continuing Healthcare and local authority commissioned social care. Continuing Healthcare is likely to be more complex and should, therefore, be more expensive as staff will require higher levels of training etc. However, some NHS organisations pay lower rates to providers than neighbouring local authorities – this must affect quality and supply of services and should be made visible within the ICS.

There is currently no specific data collected on live-in care and it is instead grouped with the visiting homecare market. This makes it challenging to understand the market and the outcomes for people that use this service.

11. What information and data does national government need, in relation to supply of care services, local authority commissioning and accountability, and markets (including occupancy, capacity and discharge)?

Supply of Care Services

- Objective: ensure that there's a consistent and adequate provision of care services across the country.
- National demand forecasting data: predict future requirements for care services based on national trends, e.g. national population projections, general health trend analyses, nationwide census data.
- Regional capacity metrics: assess the capacity across various regions to identify disparities, e.g. regional counts of care facilities, staffing levels, specialty care availability.
- Service utilisation rates: gauge the national usage rate of care services, e.g. nationwide bed occupancy rates, number of people supported at home and in other settings, utilisation of specialised services.

Local Authority Commissioning

- Objective: oversee and support local authorities in their commissioning roles, ensuring consistency and quality.
- Local Authority commissioning data: monitor the types and quantity of services commissioned by local authorities, e.g. number and type of contracts issued, service provider details, contract values.
- Budget allocation and utilisation: ensure proper funding allocation and monitor its use, e.g. national vs. local funding data, utilisation rates, unspent funds.
- Standardised contractual guidelines: ensure consistency in terms and conditions across regions, e.g. standard contract clauses, performance benchmarks, service delivery expectations.
- Track data on outcomes by local authority and ICS, e.g. delayed transfers of care, hospital readmission, prevention of escalation of need, waiting times for care services, unmet need, homecare packages handed back (with reasons), continuity of services, quality ratings, staff vacancy rates.
- Track data on cost per person vs outcomes by local authority.

Accountability

- Objective: set standards and ensure transparency and adherence across all regions.
- National Incident and Complaint Database: aggregate data to identify patterns or systemic issues, e.g. national database of complaints, frequency of specific incidents, severity levels.
- Audit and inspection summaries: review aggregated findings to ensure consistent quality and safety standards, e.g. summary of inspection results, regions requiring attention, trends in compliance.
- National Accountability Framework: provide guidelines for local accountability measures, e.g. national standards, reporting requirements, consequences for non-compliance.

Markets (including occupancy, capacity, and discharge)

- Objective: assess the health and dynamics of the national care service market.
- Market dynamics data: monitor the stability and growth of the care services sector, e.g. national data on facility openings/closures, mergers/acquisitions, market growth rates.
- National capacity and occupancy metrics: maintain a pulse on the availability and usage of care facilities nationally, e.g. total national care capacity, regional disparities, national occupancy rates.
- Discharge and transition data: ensure smooth transitions for people across various care settings, e.g. national averages for lengths of stay, discharge destinations, readmission rates.

Social Care workforce

12. What information and data do people who use care and support services and their carers need, in relation to the social care workforce?

Data are required to empower care recipients and their unpaid carers to make informed decisions, ensure the quality of care, and actively participate in the care process. Proper knowledge and transparency about the social care workforce are crucial for establishing trust and facilitating effective care outcomes.

Social Care Workforce Profile

- Qualifications and training: to ensure care recipients receive service from qualified professionals, e.g. education levels, specialised training, continued education credits.

- Experience and tenure: gauge the expertise and longevity of care providers, e.g. years in service, areas of specialisation, previous roles.
- Background checks: ensuring the safety and security of care recipients, e.g. criminal background checks, references, previous employment verification.

Workforce Availability and Accessibility

- Staff-to-Client ratios: ensuring sufficient attention and care for each individual, e.g. number of staff per client, role-based ratio (e.g. nurse-to-care recipient).
- Scheduling and availability: planning and coordination of care, e.g. staff working hours, shift patterns, on-call availability.
- Specialised care providers: for clients with specific needs, e.g. availability of specialised therapists, language proficiency, cultural competency.

Workforce Well-being and Satisfaction

- Staff turnover rates: gauge stability and continuity of care, e.g. average tenure, reasons for leaving, frequency of turnover.
- Staff satisfaction surveys: understanding the morale and satisfaction of the workforce, e.g. job satisfaction levels, areas of concern, feedback on work environment.
- Support and supervision structures: ensuring the workforce is well-supported and issues are addressed, e.g. frequency of supervisions, mentorship programs, support mechanisms.

Communication and Feedback Mechanisms

- Point of Contact Information: for ease of communication and addressing concerns, e.g. designated contact person, communication channels, response timeframes.
- Feedback and Complaint Processes: ensuring voices of care recipients and their carers are heard, e.g. process to raise concerns, resolution timelines, follow-up mechanisms.
- Client-Carer Collaboration Platforms: promote cooperative care planning and delivery, e.g. platforms/tools available, access procedures, collaboration features.

13. What information and data do care providers need, in relation to the social care workforce?

For social care providers, having a comprehensive understanding of their workforce is pivotal. This data not only ensures the delivery of high-quality care but also aids in workforce management, development, and retention. The right data allows providers to match the skills and expertise of their staff to the unique needs of their service users, ensuring optimal outcomes.

Demographic Details

- Basic personal information for identification and administration purposes, e.g. name, date of birth, address, contact details.
- Background and Origin: understanding the diversity and inclusivity of the workforce, e.g. ethnicity, gender, nationality, languages spoken.

Qualifications and Training

- Educational background: assessing suitability for certain roles, e.g. qualifications obtained, institutions attended, specialisations.
- Professional training: ensuring competence and adherence to best practices, e.g. training courses attended, certification earned, dates of completion.

Employment History and Experience

- Previous roles and employers: gaining insights into past performance and expertise, e.g. former job titles, responsibilities, durations, reasons for leaving.
- Areas of expertise and specialisation: assigning roles that best suit the employee's skills, e.g. specialised training, areas of interest, years of experience in specific domains.

Performance Metrics

- Staff retention rates.
- Staff vacancy rates.
- Hours worked per care worker.
- Continuity of care, e.g. number of different staff per person drawing on care.
- Staff utilisation rate, e.g. hours of care delivered per hours paid.
- Efficiency of rostering, e.g. number of people supported per care worker, average visit length, average travel time per hour of care delivered.
- Wage rates vs staff recruitment and retention.
- Wage rates vs care quality.
- Fee rates charged vs wage rates.
- Conversion rates of applicants to interviewees, interviewees to starters.
- Cost per starter.
- Elapsed time between advertisement and starting.
- Performance reviews and feedback: continuous improvement and identifying training or development needs, e.g. ratings, feedback from supervisors, areas of improvement, achievements.
- Client feedback: ensuring service user satisfaction and quality of care, e.g. client satisfaction scores, comments, areas of concern.

Attendance and Availability

- Shift patterns and hours worked: workforce planning and ensuring adequate staffing levels, e.g. days and hours worked, shift rotations, overtime.

- Absence Records: monitoring staff wellbeing and managing workforce allocation, e.g. reasons for absence, duration, frequency.

Professional Development and Growth

- Continued Professional Development (CPD) activities: encouraging skill advancement and staying updated with industry standards, e.g. courses attended, conferences, workshops, in-house training.
- Career progression and promotions: recognising and rewarding talent, ensuring motivation and retention, e.g. previous roles within the organisation, dates of promotions, performance milestones.

14. What information and data does local government (including /local authorities and their staff) need, in relation to the social care workforce?

Workforce Demographics

- Objective: understand the composition of the social care workforce to ensure diverse and representative staffing.
- Age and gender distribution: anticipate retirement trends and ensure staffing appropriate to meet needs of people drawing on services, e.g. age bands of employees, gender ratios in various roles.
- Ethnic and cultural Backgrounds: promote a diverse workforce that can cater to a cultural needs of communities, e.g. ethnicity breakdown, languages spoken, cultural competency training attendance.

Training and Qualifications

- Objective: ensure that the workforce is adequately trained and qualified for their roles.
- Training Records: confirm that staff receive regular and updated training, e.g. training session attendance, courses completed, certifications obtained.
- Qualification database: maintain a record of the qualifications held by staff, e.g. qualification details, professional certifications, specialised training credentials.

Recruitment and Retention

- Objective: monitor hiring trends and address issues related to staff turnover.
- Vacancy Rates: understand the scale of staffing needs, e.g. number of open positions, duration of vacancies, roles with highest vacancy rates.
- Turnover statistics: address reasons for high turnover and improve retention, e.g. number of resignations, average tenure, exit interview feedback.

Wellbeing and Job Satisfaction

- Objective: promote a healthy work environment and address concerns affecting staff morale.
- Employee Satisfaction Surveys: gauge employee morale and identify areas for improvement, e.g. overall satisfaction scores, feedback on work conditions, suggestions for changes.
- Mental and physical health metrics: ensure the well-being of staff and address burnout or health concerns, e.g. sick leave frequency, stress-related absences, wellness program participation.

Compensation and Benefits

- Objective: ensure competitive compensation and benefits to attract and retain talent.
- Salary Surveys: stay competitive in the job market and ensure fair compensation, e.g. average salaries for various roles, comparison with neighbouring regions.
- Benefits Utilisation: understand which benefits are valued by employees, e.g. uptake of health insurance, participation in pension schemes, use of additional perks.

Professional Development

- Objective: support career growth and continuous learning within the social care workforce.
- Career Advancement Data: monitor internal promotions and provide growth opportunities, e.g. number of internal promotions, professional development courses taken.
- Feedback on professional development programmes: refine and improve training and development offerings, e.g. feedback from training sessions, requests for specific courses, mentorship program participation.

15. What information and data does national government need, in relation to the social care workforce?

National Workforce Statistics

- Objective: grasp a high-level understanding of the workforce landscape across the country
- Total workforce count: assess the size and scale of the social care workforce, e.g. total number of care workers, characteristics of workforce, regional breakdowns, urban vs. rural distribution.
- Role-wise distribution: understand the breakdown of specialised roles, e.g. number of therapists, caregivers, administrative staff, etc.
- Number of registered vs unregistered professionals.
- Staff in managed care services vs personal assistants.

Workforce Mobility and Migration

- Objective: track the movement of the social care workforce, both within the country and internationally.
- Inter-regional movement data: monitor shifts in workforce distribution across regions, e.g. care workers moving from one region to another, reasons for moves (e.g. better opportunities, personal reasons).
- International migration data: understand the inflow and outflow of the care workforce on an international scale, e.g. number of foreign workers arriving, number of local workers moving abroad, countries of origin/destination.

Education and Training

- Objective: ensure a consistently well-trained workforce on a national level.
- Accredited Training Institutions: maintain a list of institutions that provide recognised training, e.g. accredited colleges, universities, and training centres offering courses in social care.
- National registration data: ensure that workers across the country meet a standardised level of training or qualification, e.g. number of registered professionals, registration renewal rates, updates to registration criteria.

Workforce Wellbeing and Advocacy

- Objective: promote and monitor the welfare of the social care workforce on a national scale.
- National Health and Wellbeing Surveys: understand the challenges and concerns of the workforce, e.g. mental health metrics, burnout rates, work-life balance feedback.
- National workforce rights and advocacy initiatives: promote fair treatment and rights for all workers, e.g. union membership, introduction of worker rights campaigns, feedback on national policies, engagement with worker unions.

Future Projections

- Objective: anticipate the future needs and trends of the social care workforce.
- Workforce Demand Projections: plan for future workforce needs based on national trends, e.g. predicted growth of the elderly population, increasing need for specialised care, urbanisation trends.
- Training and Education Projections: ensure the educational infrastructure is prepared to train future care workers, e.g. anticipated number of students enrolling in care-related courses, infrastructure expansion plans.

Skills for Care currently collate data on the social care workforce, and this is broken down by services. Data collected are helpful but currently include only 50 per cent of providers.

There is very limited data collected on Personal Assistants and micro-providers. This is a gap in the data available to local authorities. We also believe it is in the public interest for delivery of all personal care and healthcare services, as defined in the legislation, to be regulated, regardless of a careworker's employment status.

There is increasing interest from local authorities in promoting the use of micro-providers. Within our membership, we have come across instances where a member of public or a previous employer wished to raise a fitness to practise complaint about a careworker but had no route to do so. Professional registration for those working in social care, with special priority given to Personal Assistants, would be one way of beginning to address this issue.

Unpaid carers

16. What information and data do people who use care and support services and their carers need, in relation to the population of unpaid carers?

The population of unpaid carers in the UK plays a pivotal role in the health and social care system. Understanding their demographics, the nature of the care they provide, and the challenges they face is crucial for both policy-making and for ensuring that both carers and those they care for receive the support they need.

Population Size and Distribution

- Total number of unpaid carers in the UK.
- Regional distribution of unpaid carers.
- Urban vs. rural distribution.

Age and Gender Distribution

- Age groups most likely to be unpaid carers.
- Gender breakdown of unpaid carers.

Duration and Intensity of Care

- Average number of hours spent caring per week.
- Long-term vs. short-term care situations.

Nature and Scope of Care

- Types of Care provided.
- Personal care (e.g. bathing, dressing).
- Medical care (e.g. administering medications).
- Emotional and social support.
- Relationship to Care Recipient.
- Proportion of carers caring for parents, spouses, children, or others.
- Distance between carer and care recipient.

Impact on Carers

- Physical and mental health.
- Data on stress levels among unpaid carers.
- Physical health challenges faced by carers.
- Mental health issues, including depression and anxiety rates.
- Financial impact.
- Loss of income due to caregiving responsibilities.
- Out-of-pocket expenses related to care.
- Social and personal impact.
- Social isolation rates among carers.
- Impact on personal relationships and leisure activities.

Support and Resources for Carers

- Awareness and access.
- Knowledge of available support services.
- Barriers to accessing support.
- Training and education.
- Availability of training resources for carers.
- Educational materials on specific conditions or challenges.
- Financial support.
- Information on benefits and grants available to carers.
- Charities and organisations offering financial assistance.

17. What information and data do care providers need, in relation to the population of unpaid carers?

For social care providers, understanding the vast and varied landscape of unpaid carers in the UK is essential. By gathering and analysing relevant data, providers can enhance their services, foster collaboration, and ensure that both unpaid carers and their recipients receive the comprehensive support they require.

Demographic Data on Unpaid Carers

- Population size and distribution.
- Total number of unpaid carers in the UK.
- Regional distribution of unpaid carers, to understand localised demands.
- Urban vs. rural distribution to tailor service provision.
- Age and gender distribution: age groups most likely to be unpaid carers, to target specific support services. Gender breakdown of unpaid carers to address gender-specific challenges.
- Ethnic and cultural background: understanding cultural sensitivities and tailoring support accordingly. Addressing potential language barriers in service provision.

Nature and Scope of Care

- Types of care provided.
- Data on the range of care, from personal, to medical, to emotional support.
- Identifying gaps where professional services might be needed.
- Relationship to care recipient.
- Understanding the dynamics of care, whether for parents, spouses, children, or others.
- Gauging the emotional intensity of care situations.

Challenges Faced by Unpaid Carers

- Physical and mental health.
- Rates of burnout and fatigue among carers.
- Mental health challenges, including depression and anxiety.
- Financial Strain: loss of income or employment due to caregiving responsibilities. Financial burdens related to care provision.
- Training and Knowledge Gaps: areas where carers feel under-equipped or lacking in skills. Need for information on specific conditions or challenges.

Support and Collaboration Opportunities

- Existing support structures.
- Awareness among carers of current support services.
- Feedback on the effectiveness and accessibility of existing services - potential collaborative initiatives, opportunities for joint training sessions for professional and unpaid carers.
- Shared resource platforms for information dissemination.
- Feedback Mechanisms: establishing channels for unpaid carers to provide feedback on social care services; regular surveys or forums to understand evolving needs.

18. What information and data does local government (including /local authorities and their staff) need, in relation to the population of unpaid carers?

Census 2021 found that in England and Wales there are 5 million people a week who are providing unpaid care to a family member, loved one or other. This includes 1.5 million people who are providing over 50 hours of care a week. Unpaid carers play a vital role in supporting older and disabled people, but caring can be both physically and mentally demanding. Without adequate support, the demands of caring can become too much and cause detrimental impact to their mental and physical wellbeing.

By comprehensively assessing data on unpaid carers, local governments can tailor their resources, policies, and initiatives to provide robust support for the invaluable unpaid carers within their communities.

Demographic Details

- Objective: understand the general profile of unpaid informal carers in the region.
- Age and Gender Distribution: gauge the age and gender spectrum of those undertaking care responsibilities, e.g. age bands of carers, gender ratios.
- Ethnic and Cultural Backgrounds: tailor support services to cater to diverse cultural needs, e.g. ethnicity breakdown, languages spoken, cultural traditions regarding caregiving.

Care Recipient Information

- Objective: understand the needs and conditions of those being cared for.
- Relationship to carer: recognize the nature of care relationships (e.g. parent-child, spousal, e.g. number of spousal carers, child carers, sibling carers, etc.
- Health conditions of care recipients: tailor resources and support based on the specific needs of care recipients, e.g. number of people with dementia, physically disabled individuals, terminally ill patients, etc.

Duration and Intensity of Care

- Objective: grasp the extent of caregiving responsibilities borne by unpaid carers.
- Hours of care provided weekly: gauge the intensity of caregiving duties and potential for carer burnout, e.g. number of carers providing 20+ hours of care weekly, those offering occasional care, etc.
- Duration of care role: understand long-term caregiving trends and the need for sustained support, e.g. carers who've been providing care for 1 year, 5 years, 10+ years, etc.

Financial and Employment Impact

- Objective: determine the financial strain and work-related challenges faced by carers.
- Employment status: understand how caregiving impacts employment, e.g. number of full-time employed carers, part-time, unemployed due to caregiving responsibilities.
- Financial Assistance: assess the need for financial support or benefits for carers, e.g. carers receiving financial aid, those in need of assistance, types of financial challenges faced.

Support Services Utilisation

- Objective: monitor the uptake of available resources and services for carers.

- Use of respite services: assess the demand and effectiveness of respite care options, e.g. number of carers using respite care, frequency, feedback on services.
- Participation in carer support groups: gauge the demand for and value of peer support and community resources, e.g. attendance at support meetings, online community participation, feedback on support initiatives.

Wellbeing and Health of Carers

- Objective: ensure the mental and physical health of unpaid carers.
- Health and Wellbeing Surveys: understand challenges, stressors, and health concerns specific to carers, e.g. mental health metrics, burnout rates, physical health challenges.
- Access to Healthcare: ensure carers are also looking after their own health needs, e.g. regular health check-ups, counselling or therapy sessions.

19. What information and data does national government need, in relation to the population of unpaid carers?

Nationwide Demographics of Carers

- Objective: gain a comprehensive understanding of the scale and scope of unpaid caregiving across the country.
- Total number of carers: grasp the magnitude of the informal caregiving landscape, e.g. total number of carers, regional breakdowns, urban vs. rural distribution.
- Age and Gender Distribution: identify specific demographic groups that might require tailored support, e.g. age bands of carers, gender ratios, comparison across regions.

Nature and Reason for Care

- Objective: understand the diverse caregiving needs across the country.
- Underlying Health Conditions: gauge the primary health concerns leading to the need for care, e.g. number of people living with dementia, individuals with disabilities, those with chronic illnesses, etc.
- Relationship to care recipient: understand the familial or relational context of care, e.g. parent-child caregiving, spousal care, sibling care, neighbour or friend care.

Economic Impact on Carers

- Objective: recognise the broader economic implications of unpaid caregiving.
- Lost productivity and employment impact: gauge the effect of caregiving responsibilities on the national workforce, e.g. percentage of carers leaving full-time jobs, reduced hours, unemployment rates among carers.

- Financial dependency and support: understand the economic challenges faced by carers, e.g. carers relying on government benefits, financial strain indicators, need for subsidies or aid.

Carer Health and Well-being

- Objective: prioritise the welfare of the carers, ensuring they are not neglected.
- Mental and physical health metrics: monitor the well-being of carers on a national scale, e.g. stress levels, instances of burnout, access to healthcare, reported illnesses.
- Access to support services: ensure national provisions for carer support are adequate and accessible, e.g. uptake rates for counselling services, attendance in national carer support programmes.

Policy Impact and Feedback

- Objective: continuously refine national policies based on carer feedback and outcomes.
- Effectiveness of national carer support initiatives: gauge the success and areas of improvement for existing programmes, e.g. feedback on respite care services, financial aid programs, and training resources.
- Carer advocacy and representation: ensure carers have a voice in national policy-making, e.g. engagement with carer representative groups, feedback mechanisms in place, carer participation in policy discussions.

Contingency and infectious control measures

20. What information and data do people who use care and support services and their carers need, in relation to contingency and infectious disease control measures?

For individuals who use care and support services, as well as their carers, understanding contingency and infectious disease control measures is crucial. This ensures the safety and well-being of both the care recipient and the carer, especially during outbreaks or pandemics.

Understanding Contingency Measures

- Definition and Importance: explanation of what contingency measures are. Why they are vital for care and support services.
- Implementation Procedures: steps to take when a contingency plan is activated. Roles and responsibilities of care providers and carers.
- Communication Channels: how care recipients and carers will be informed of changes or emergencies. Reliable sources of information and updates.

Infectious Disease Control Measures

- Basic Hygiene Practices: Hand hygiene: proper washing and sanitising techniques. Respiratory hygiene: correct coughing/sneezing etiquette. Safe disposal of waste, including medical waste.
- Personal Protective Equipment (PPE). Types of PPE relevant to care settings. Correct procedures for donning and doffing PPE. Disposal and sanitisation of used PPE.
- Isolation and Quarantine Procedures: When and how to isolate a care recipient. Procedures for carers to follow if they suspect they are infected. Duration and protocols for quarantine.

Monitoring and Reporting

- Symptom Tracking: common symptoms of prevalent infectious diseases. How to monitor and record symptoms in care recipients.
- Reporting Mechanisms. Who to report to if symptoms are observed. How to report: online platforms, hotlines, etc.
- Regular Health Checks. Frequency of health checks for care recipients and carers. Procedures and tools for conducting these checks.

Access to Resources and Support

- Medical Supplies. List of essential medical supplies for infectious disease control. Where and how to procure them.
- Training and Workshops. Available training sessions on infectious disease control for carers. Online resources and workshops for continuous learning.
- Support Networks. Helplines and support groups for carers. Mental health resources for dealing with the stress of care during outbreaks.

21. What information and data do care providers need, in relation to contingency and infectious disease control measures?

For social care providers, the dual challenges of contingency planning and infectious disease control require a comprehensive approach. By ensuring they have access to the right information and data, and by fostering a culture of preparedness and continuous learning, care providers can ensure the safety and well-being of all involved.

Contingency Planning

- Risk Assessment: identification of potential risks in care settings. Evaluation of the likelihood and impact of these risks.
- Emergency Protocols: detailed action plans for various emergency scenarios. Communication strategies to inform staff, care recipients, and their families.

- Resource Allocation: stockpiling essential supplies for emergencies. Budgeting for unexpected costs related to emergency situations.

Infectious Disease Control Measures

- Prevention Protocols: hygiene standards to be maintained in care settings. Training for staff on infectious disease prevention.
- Detection and Reporting: symptom monitoring tools and protocols. Reporting mechanisms for suspected or confirmed cases. Collaboration with health authorities for timely reporting.
- Quarantine and Isolation Procedures: Designation of isolation areas within care facilities. Protocols for transferring individuals to medical facilities if needed.
- Personal Protective Equipment (PPE). Inventory management for PPE. Training on the correct usage and disposal of PPE.

Staff Training and Support

- Regular Training Sessions: frequency and content of training on contingency and infectious disease control. Feedback mechanisms to update and improve training content.
- Mental Health Support: resources for staff to cope with the stress of care during outbreaks. Counselling services and support groups.

Communication with Families and Carers

- Regular Updates: channels for communicating with families about the health status of care recipients. Transparency in sharing information about any outbreaks or cases within the facility.
- Involvement in Decision Making: mechanisms for families and carers to be involved in care decisions during emergencies. Feedback loops for families to share concerns and suggestions.

22. What information and data does local government (including /local authorities and their staff) need, in relation to contingency and infectious disease control measures?

Disease Surveillance Data

- Objective: monitor and identify potential outbreaks in real-time.
- Confirmed cases and locations: understand the geographical spread and intensity of an outbreak, e.g. number of cases by neighbourhood, infection hotspots.
- Symptom reporting from health and care services: detect emerging diseases or unusual spikes in symptoms, e.g. number of infectious disease symptoms reported in clinics, care homes, homecare agencies, instances of rare diseases.

Population Demographics and Vulnerabilities

- Objective: tailor responses to the specific needs of the population.
- Population density and urban clusters: identify areas that may be at higher risk due to crowding, e.g. population per square kilometre, identified crowded neighbourhoods.
- Vulnerable population data: offer targeted support to those most at risk, e.g. number of elderly residents, individuals with chronic illnesses, immunocompromised individuals.

Health Infrastructure Capacity

- Objective: ensure that health facilities can cope with increased demand during outbreaks.
- Hospital bed availability: manage and allocate resources effectively, e.g. number of beds occupied, ICU bed availability.
- Inventory of medical supplies: prevent shortages and allocate resources where needed, e.g. stock levels of PPE, testing kits, ventilators, essential medicines.

Travel and Movement Data

- Objective: track and manage the potential spread of infectious diseases.
- Local Travel Patterns: predict and manage potential disease spread, e.g. public transport usage data, major events or gatherings.
- Incoming and outgoing travel data: assess risk from outside regions or countries, e.g. number of travellers from high-risk areas, quarantine measures in place.

Public Response and Behaviour

- Objective: gauge public compliance and sentiment towards measures.
- Adherence to guidelines: understand how effectively the public is following guidelines, e.g. percentage of people wearing masks, following social distancing.
- Public feedback and concerns: address misconceptions and improve public health campaigns, e.g. common questions or misconceptions, feedback on local guidelines.

Contingency Plans and Resources

- Objective: ensure readiness to deal with escalating situations.
- Status of emergency stockpiles: ensure sufficient backup supplies during prolonged outbreaks, e.g. levels of emergency food stocks, backup medical supplies.
- Availability of emergency personnel: have a roster of personnel ready to deploy, e.g. number of available emergency responders, trained volunteers.
- Data on local care providers and voluntary groups that may require support and supplies.

23. What information and data does national government need, in relation to contingency and infectious disease control measures?

National Disease Surveillance Data

- Objective: monitor and identify potential outbreaks across the country.
- Confirmed cases and regional distribution: grasp the nationwide spread and intensity of the disease, e.g. total number of cases by local authority area, national hotspots.
- Mortality and recovery rates: assess the severity and track the progression of the disease, e.g. number of recoveries vs. deaths, comparison across regions.

International Context and Data

- Objective: understand the global context to manage international transmission risks.
- Global infection rates and trends: predict potential international transmission and assess risk, e.g. cases reported by neighbouring and partner countries, global hotspots.
- Travel data and entry points: monitor and control borders to prevent disease importation, e.g. number of international travellers, screenings at ports and airports.

Health System Capacity and Readiness

- Objective: prepare the national health and care system for potential surges in cases.
- National health and care infrastructure capacity: understand the capabilities and limits of the health and care system, e.g. total hospital beds, ICU capacities, nationwide ventilator availability, ability of care homes and homecare services to support people drawing of services and care staff.
- Health and care workforce data: deploy human resources effectively and prevent burnout, e.g. number of available healthcare workers, areas with staff shortages.

Vaccine and Treatment Development

- Objective: facilitate and track progress on curative and preventive solutions.
- Research and clinical trial data: support and accelerate promising studies, e.g. current stages of vaccine trials, effectiveness of treatments under study.
- Production and distribution plans: ensure rapid and equitable access once available, e.g. manufacturing capabilities, distribution logistics.

Economic and Social Impact Data

- Objective: gauge the broader societal implications and support affected sectors.
- Economic Impact Reports: inform economic relief measures and interventions, e.g. industries most affected, unemployment rates, GDP impact.
- Social behaviour and compliance data: understand public sentiment and ensure effective communication, e.g. level of adherence to national guidelines, public sentiment analysis.

National Contingency Resources

- Objective: ensure nationwide readiness for various outbreak scenarios.
- National Emergency Stockpile Status: maintain and utilise backup supplies effectively, e.g. national reserves of essential medicines, testing kits, PPE stocks.
- Emergency Response Strategy: have a clear plan to handle escalating situations, e.g. quarantine facility availability, rapid response teams.

The Covid-19 pandemic highlighted the lack of sufficient data to track infectious disease monitoring. A range of data, including some currently collected by Capacity Tracker, will be useful indicators including vaccine uptake, PPE supply, notifiable disease incidence by setting, and the number of local authorities with updated emergency plans in place.

This year the National Cyber Security Centre **issued an alert** of an increased risk of cyber-attacks where systems are poorly protected. As a membership organisation, we know first-hand how devasting these attacks can be and how much damage they can inflict on the provider and the subsequent effect this has on people who rely on care services. Data collected on the safety measures businesses have in place, and sharing cases of best practice can support the prevention of such attacks. Similarly, information and data from providers that have fallen victim to such attacks can help to implement contingency plans to protect the sector as a whole.

Overall, what information and data is most crucial in your opinion?

24. Data Needs for Sustainable and High-Quality Domiciliary Care in the UK

Demographic and Health Data

- Objective: Understand in detail the care needs of the UK population.
- Population Age Distribution: Older populations typically have greater care needs, e.g. proportion of the population above 65, projected growth of elderly population.
- Prevalence of Chronic Diseases and Disabilities: These populations often require ongoing care support, e.g. number of people with dementia, mobility issues, or chronic illnesses.
-

Current Care Service Utilisation

- Objective: Assess and manage effectively existing and future demand and capacity.
- Domiciliary Care Service Usage: Understand the current scale of service usage and identify gaps. Number of people using homecare. Number of people paying for their own care vs those funded by the State; frequency, and duration of care received. Unmet need. Population need projections.
- Care Home Admissions vs. Domiciliary Care: Determine preference and suitability of care setting, e.g. rate of admissions to care homes, comparison with homecare uptake.
- Benefits and costs of homecare relative to other care settings.

Workforce Data

- Objective: Ensure adequate staffing and prevent burnout.
- Number of Domiciliary Care Workers: maintain adequate staff to patient ratios, e.g. total homecare workers, distribution across regions.
- Training and Qualification Levels: ensure the workforce is adequately trained for complex care needs, e.g. percentage of staff with specialised training, ongoing professional development.

Quality and Safety Metrics

- Objective: Uphold high standards of care.
- Audit and inspection: up-to-date quality assurance, quality ratings
- Incidents and Complaints: identify areas of concern and improve services, e.g. number of reported incidents, nature of complaints.
- Patient and Carer Feedback: Direct feedback is essential to understand the lived experience and improve services, e.g. satisfaction surveys, feedback forms.

Financial Data

- Objective: Ensure financial sustainability of domiciliary care services.
- Funding Sources and Levels: understand the financial health and ensure services are adequately funded, e.g. amount of government funding, private payments, insurance contributions.
- Expenditure Breakdown: Identify areas of high cost and potential savings, e.g. efficiency of rostering, reducing travel time, share training, administrative expenses.

Technological and Innovative Solutions

- Objective: Enhance the efficiency and effectiveness of care.
- Adoption of Technology in Care: Technology can improve the quality of care and reduce costs, e.g. remote health monitoring, assistive devices, robotics, digital health records.
- Research and Innovation in Domiciliary Care: stay updated with the latest methods and tools for better care, e.g. studies on new care methodologies, pilot programs.

The lack of comprehensive and standardised data surrounding self-funders prevents effective support and improving outcomes for people in social care. Too little information is known about how a large portion of the market fund their care, and it is difficult to understand overall capacity and ensure that we are meeting demand.

Data on social care also need to be collected from local authorities and the NHS, and this shared with providers as well as with central and local government. It is important to ensure that there are not multiple competing data requests from providers, any information requested should be easy for them to complete. More time spent on collecting the data on the increased cost of delivering care and the more time spent away from direct care delivery is particularly important. It is worth reviewing where best to collect the data, for example hand back of contracts and those that are difficult to place will be better collected by the local authority than the provider.