

Scottish Public Health Network (ScotPHN)

**Palliative and End of Life Care – Renfrewshire HSCP
Data Plan and Data Sources**

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**(Whole system map of palliative and end of life care provision in
Renfrew HSCP - Updated March 2018)**

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Acronyms & Abbreviations

ACP	anticipatory care planning
CHI	Community Health Index
CMHT	community mental health team
CC	Continuing Care
DiUPR	death in usual place of residence
DWP	Department for Work and Pensions
ECS	Emergency Care Summary
GLS	Geriatric Long Stay
HSCNA	health and social care needs assessment
HSCP	Health and Social Care Partnership
HLE	Healthy life expectancy
IoRN	Indicator of Relative Need
ISD	Information Services Division
IHI	Institute for Healthcare Improvement
ICD	International Classification of Disease
KIS	Key Information Summary
NPF	National Performance Framework
NRS	National Records Scotland
NSS	National Services Division
OOH	Out of hours
PELC	palliative and end of life care
PoA	Power of Attorney
PTI	Practice Team Information
PAG	project advisory group
PHE	Public Health England
QoF	Quality and Outcomes Framework
RPD	Renfrewshire Development Project
SAS	Scottish Ambulance Service
SHeS	Scottish Health Survey
SHCS	Scottish Household Conditions Survey

SIMD	Scottish Index of Multiple Deprivation
SMR	Scottish Morbidity Record
SPARRA	Scottish Patients at Risk of Readmission and Admission
UCD	Unscheduled Care Datamart
WEMWBS	Warwick-Edinburgh Mental Health Wellbeing Scale
WTE	whole time equivalent

Introduction

This paper is the output of work undertaken from December 2016 through March 2017 on behalf of the Renfrew Health and Social Care Partnership (HSCP). It has been supported and advised by a multi-disciplinary and multi-organisational (local and national) project advisory group (PAG).

This document is intended as a companion to a forthcoming health and social care needs assessment (HSCNA) that will be undertaken to inform the future delivery of PELC services in the locality in a process designed to engage key stakeholders in decision-making.

An initial workshop with the PAG was undertaken in December 2016. The output from this workshop was a high level map of the whole system model of palliative and end of life care (PELC) service provision in the Renfrew HSCP area (Appendix 1). This provided a starting point for the exploration of potential data sources that could be used to describe the health and social care use of people from the Renfrew HSCP in the last year of their life. These data will help us understand who is using health and social care services in the last year of their life, why they are using them, where and how they are accessing them. A whole system approach will enable key stakeholders to identify what changes can be made to better meet peoples preferences and priorities for care.

This paper describes the range of routine data available to inform local health and social care needs assessment of palliative and end of life care (PELC) that were identified through this project. In addition to highlighting existing high quality data sources, the report identifies information gaps and opportunities to develop existing or develop new data sources to fill these.

The project initially focused on collating and appraising data sources relevant to PELC service provision in the Renfrew HSCP area. However, given the breadth of health and social care data that we were able to identify and the availability of data at national, regional and local levels, we believe that this report will be of interest to people using, designing and delivering PELC in a range of settings and localities across Scotland.

The report is presented in three sections. The first considers the data available to create an individual level linked dataset to examine health and social care use. The second considers more broadly supplementary aggregate data that could be used to create a locality profile providing valuable background and contextual information on local populations to inform the HSCNA process. The third section describes a data analysis plan using individual level linked data from the national and local dataset identified in the Renfrew HSCP to examine health and social care use in the last

year of life. We believe that these analyses could be replicated at national and local level across Scotland to inform other local HSCNA.

1. Individual-level linked dataset for health and social care

The section that follows describes the sources of routinely collected and collated data that have the potential to be linked to create an individual level patient record to describe the pattern of health and social care use in a cohort of people during the last year of life.

Most of the data sources identified are collected and collated at a national level. To fill information gaps where national data are unavailable we have, where possible, identified supplementary local data sources from the Renfrew HSCP area. It is likely that in localities across Scotland rich data collected and collated for audit, evaluation and quality improvement purposes will be also be available on local systems.

For each data source we provide a brief overview of what data are available and where appropriate signpost via web-links to further information. It is important to remember that many of these datasets require significant manipulation by a skilled statistician prior to analysis and thereafter careful interpretation of findings, acknowledging the strengths and limitations of the data, the local context within which care is being delivered and the wider policy drivers.

1.1 Mortality data

1.1.1.1 Death certificates, National Records Scotland (NRS)

Death certificates contain individual level data on basic demographics, including age, sex, ethnicity (since 2012), marital status, cause and place of death; occupation and postcode can be used to derive information on socioeconomic status (SIMD). These data are routinely collected and collated for all deaths in Scotland, providing complete national coverage. It would be anticipated that the quality and accuracy of death certification in Scotland has improved since the death certificate review service was initiated in April 2015; it is important to consider the potential impact of the introduction of this service if temporal trends in cause of death are being examined.

Death certification data are routine linked to hospitalisation data in Scotland. Place of death is routinely reported by ISD in their cancer statistics. An indicator for death in usual place of residence (DiUPR) is not currently available in Scotland but would be desirable. Careful consideration should be given to categorisation of cause of death prior to analyses. It is widely recognised that some conditions are under-recorded on death certification – for example dementia and renal disease – which may necessitate examination of not only ‘underlying’ cause of death, but inclusion of

death certificates that contain 'any mention' of the condition. It is also important to give careful consideration to the International Classification of Disease (ICD) 10 categories (ICD 9 prior to 2010/11) used to group cause of death in analyses. NRS adopt a standard approach to producing mortality statistics, examining underlying cause of death categorised according to ICD chapter. It may however be desirable to create profiles for specific causes of death, for example for liver disease, which necessitates moving beyond these boundaries. Public Health England (PHE) have carried out work in this area so there is potential to extract common learning from their approach and consider alignment to allow comparison between the devolved nations.

Finally, it is important to note that there are limitations in using death certificate data to identify individuals that may have a PELC need. For example, a person may have had a terminal cancer diagnosis in the last year of their life but died in a road traffic accident; because cancer did not cause or contribute to their death this would not appear on their death certificate. Further information about death certificate data in Scotland can be found at:

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths>

1.2 Hospitalisation data

A range of hospitalisation data is routinely collected and collated in the Scottish Morbidity Record (SMR) and various other datamarts maintained by Information Services Division (ISD) of National Services Scotland (NSS).

1.2.1 SMR01 Acute hospital admissions and day cases, ISD

SMR01 contains individual, episode level data on everyone admitted to, or attending as a day case, an acute hospital in Scotland. Information recorded includes type of admission (emergency or elective), admitting specialty, ICD 10 discharge diagnoses (up to 6) and operations, length of stay and discharge destination. Demographic data include age, sex, ethnicity (generally poorly recorded) and SIMD. Routine deterministic data linkage via the Community Health Index (CHI) number is used to create the Scottish Morbidity Database, linking SMR01, SMR04 (Mental Health Dataset), SMR06 (Cancer Registry) and National Records of Scotland Death Records.

These are high quality data with a high level of population coverage. This dataset has been collected and collated since 1981; data are released regularly ensuring they are up to date. The data do however require careful manipulation and interpretation. It is important to note that data from those independent hospices that submit an SMR return for their in-patient activity will be held within SMR01, however not all independent hospices submit an SMR return. It would therefore be important

to ensure that hospice data are removed and analysed separately. Further information about the SMR01 dataset can be found at:

<http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets//SMR01-General-Acute-Inpatient-and-Day-Case/>

It may also be possible to identify people admitted to NHS Continuing Care (CC) and Geriatric Long Stay (SMR01 GLS) wards in this dataset. Additional aggregate data on CC/GLSW can be found in the Balance of Care Census, which is collated by ISD using data submitted by the territorial NHS boards. Further information can be found at:

<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=12&SubID=47>

1.2.2 SMR04 Mental Health In-patient and Day Case, ISD

This dataset contains individual, episode level data on everyone admitted to, or attending as a day case, a psychiatric hospital in Scotland. Information recorded includes mental health diagnoses, length of stay health diagnoses, whether detained under mental health legislation, and basic demographic information (as for SMR01). Routine deterministic data linkage via the CHI number is used to link these data to SMR01 (Acute in-patient and day case), SMR06 (Cancer Registry) and National Records of Scotland Death Records in the Scottish Morbidity Database.

These data are high quality with very high level of population coverage. Whilst it would be desirable to combine acute (SMR01) and psychiatric (SMR04) hospitalisations for analysis it is important to note that psychiatric hospital admissions can be very different from acute hospital admissions and may include long periods where the patient is 'on pass' which may skew length of stay analyses. Accounting for the fact that some psychiatric hospitalisations can be very lengthy, data are submitted to ISD on both admission and at discharge. It is important that differences in SMR01 and SMR04 are recognised when analysing and interpreting the data. Further information on the SMR04 dataset can be found at:

<http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets/SMR04-Mental-Health-Inpatient-and-Day-Case/>

1.2.3 SMR06 Cancer Registry, ISD

SMR06, the Scottish Cancer Registry, collects individual level information on people diagnosed with malignant (and some benign) tumours. In addition to basic demographics detailed clinical information about the tumour is recorded including site, histology, behaviour, and for some tumours grade, stage and treatment information. These data can be deterministically linked using the CHI number to the Scottish Morbidity Database. Further information on the Scottish Cancer Registry can be found at:

<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=5&SubID=8>

1.2.4 Delayed discharges, ISD / NHS Boards (EDISON)

NHS territorial health boards submit monthly data on delayed discharges to ISD who publish quarterly statistics. Data are managed in the EDISON system. The presence of a CHI number opens the possibility of data linkage with other datasets including the Scottish Morbidity Dataset. Within a cohort of patients this would allow the identifications of those patients that experienced a delayed discharge, the reason for their delayed discharge, the number of additional bed days accounted for by the delay in discharge and whether an individual died in hospital during a delay in discharge. Changes in the recording and reporting of delayed discharges were introduced in July 2016 therefore when examining trends it would be important to consider the potential impact this may have had on the data. Further information on delayed discharges can be found at:

<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=1&SubID=48>

<http://www.jitscotland.org.uk/resource/edison/>

1.2.5 SMR00 Outpatient appointments and attendances, ISD

The SMR00 dataset contains individual, episode level data on new and follow up appointments at outpatient clinics across Scotland (excluding Accident & Emergency and Genitourinary Medicine). In addition to basic demographic information, information on clinical specialty and operations/procedures undertaken is also collected. SMR00 data are not routinely linked to the Scottish Morbidity Database, but adhoc linkages can and have been carried out using the CHI number. Further information about SMR00 can be found at:

<http://www.ndc.scot.nhs.uk/Data-Dictionary/SMR-Datasets/SMR00-Outpatient-Attendance/>

1.2.6 Accident & Emergency Datamart (A&E2), ISD

The A&E2 datamart was established in 2007 and contains episode level data collected on all A&E attendances across Scotland, including basic demographics, ICD coded discharge diagnoses (since 2010) and discharge location. Smaller minor injuries units and community hospitals may submit aggregate rather than episode based data only (site submitting episode level data count for around 94% of all attendances). Detailed information is recorded on injuries (accidental and non-accidental). Information on presenting complaint is recorded in free text and by broad ICD 10 coded disease categories and diagnostic grouping which are of limited value in the present study. It is possible to identify the whether people attending A&E were subsequently admitted to hospital. It is also possible to identify deaths in the emergency care setting.

These data have recently been routinely linked to data from NHS24, Scottish Ambulance Service (SAS) and out of hours (OOH) primary care data in an Unscheduled Care Datamart (UCD); in turn this has been linked to the Scottish Morbidity Database. Further information on the A&E datamart is available at:

<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=1&SubID=3>
http://www.isdscotland.org/Health-Topics/Emergency-Care/Emergency-Department-Activity/Data-Quality/Data_Recording_Manual_Oct13.pdf

1.2.7 Unscheduled Care Datamart (UCD), ISD

Patient level data from NHS24, SAS, A&E are now routinely collected and collated to create a complete picture of out of hours care; data are available from 2011 onward. Data include patient demographics, date and time of attendance, presenting complaint and outcome of attendance. Linkage of the dataset has allowed the creation of complete patient pathways describing how people use these services. These data have been linked to the out of hours primary care dataset and also the Scottish Morbidity Database. Additional information can be found at:

<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=1&SubID=111>
http://www.isdscotland.org/Health-Topics/Emergency-Care/Patient-Pathways/unscheduledcare_background.pdf

1.2.8 Out of Hours Primary Care, ISD

Introduced April 2014, the GP Out of Hours (OOH) datamart routinely collects and collates patient level data on all contacts with OOH primary care services through the ADAstra patient management system, in use across all out of hours primary care services in Scotland. Data includes source of referral, type of consultation, diagnosis (READ coded, may contain multiple fields), outcome of referral and whether Emergency Care Summary (ECS) and Key Information Summary (KIS)¹ were accessed. Importantly, information about whether the ECS is completed and if so what information was contained therein is not recorded. These data have been linked to the UCD (above) and the Scottish Morbidity Database. Further information can be found at: <http://www.isdscotland.org/Health-Topics/Emergency-Care/GP-Out-of-Hours-Services/docs/OOH-data-set.pdf>
<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=1&SubID=113>

¹ The KIS is an extension of the ECS which contains detailed information relating to a persons past medical history, baseline function and clinical status, triggers for deterioration, current care arrangements, ceilings of treatment, preferences for care and death, palliative care information, legal issues such as Power of Attorney and DNACPR status.

1.2.9 TRAKcare, (Most) NHS Boards

Most territorial health boards in Scotland now use the TRAKcare (Intersystems Corp.) patient management system, which contains patient level information tracking patient journeys across the acute sector. Operationally the functionality of the TRAKcare system varies according to the options purchased by the host board and the degree of local customisation. Local interrogation of the TRAKcare system to inform the design and delivery of services in NHSGGC has been limited however in other areas, for example NHS Lothian, TRAKcare has been used for this purpose. Referrals made within the acute sector, for example to hospital-based specialist palliative care teams are recorded in TRAKcare. It may also be possible to use TRAKcare to explore the activity of disease specific clinical nurse specialists who play an important role in the holistic management long-term conditions and delivery of PELC often across care settings. Detailed information on out-patient attendances including reviews by allied healthcare professionals are recorded; this dataset may be preferable to SMR00 for analysing out-patient attendances and is the only dataset that will capture day hospital attendance. The presence of a CHI number means that this could be linked to Scottish Morbidity Dataset and UCD.

We have not been able to establish what information from the KIS (including ACP and DNACRP documentation), if any, is accessible via TRAKcare in NHSGGC. In NHS Lothian work has been undertaken to examine the use of the KIS in the acute sector and develop the TRAK systems to link with the KIS dataset. Further exploration, within appropriate local and national information governance frameworks, of the recording of patient preferences for care within electronic patient records in the acute sector is warranted.

Referrals to services outside of the acute sector, for example community specialist palliative care teams or social work, are not recorded in Trakcare. Within the acute sector referrals to some services, for example chaplaincy, are not routinely recorded either.

Following discussions with health intelligence colleagues in NHSGGC, it became apparent that we would not be able to interrogate Trakcare to explore referrals to the hospital-based specialist palliative care team or other disease specific clinical nurse specialists for this project. We have however identified local audit data collected by the hospital-based specialist palliative care team that will allow us to examine this aspect of care in the Renfrew cohort.

It is likely that disease specific clinical nurse specialists record similar data for local audit and quality improvement that could be utilised however given the potential number of clinical specialities involved in care of this cohort, approaching teams would be prohibitive. Were future analyses to focus on disease specific groups, this option could be explored further.

1.3 Community-based services

1.3.1 Primary care

At the time of writing there was no nationally available dataset for activity in primary care. Information from primary care was previously collected, collated and reported through the Practice Team Information Programme (PTI) and the Quality and Outcomes Framework (QoF) reporting. At the time of writing SPIRE, the Scottish Primary Care Information Resource Project, a new system being developed to extract information from GP practices, is not fully operational. Further information on SPIRE can be found at: <http://spire.scot>

It may be possible to approach individual GP practices in the Renfrew HSCP area and seek permission to extract patient level data from their systems. Experience from the Renfrewshire Development Project (RPD)² suggests that this is achievable but complex with many information governance issues that would need to be resolved, which may prove prohibitive in terms of time and resource.

Lack of primary care data is a major information deficit, not least because of the increasing focus in delivering care in community based settings and the central role of the primary care team in achieving this. It would be desirable to have information not only on the activity of the primary care team in the last year of life, for example the number of consultations with a general practitioner, but also how well PELC needs are being identified and met in primary care. A proxy measure for the latter might be the use of anticipatory care planning (ACP). Again experience from the RDP suggests that it would be important to capture information on not just the number of ACP completed but also the quality of the ACP.

1.3.2 Community prescribing: prescribing information system, ISD

Hospital prescribing data is available at aggregate level only. However, patient level data on all prescriptions (community and hospital) written in Scotland that are *dispensed* in the community are available in this dataset. These data contain a CHI number and can therefore be linked to other ISD datasets. It is important to note that these data require very careful analyses and interpretation and would benefit from input from an analyst with experience using them. Only prescriptions filled are recorded and inferences about compliance cannot be made. Data on over the counter medication are not available. Careful consideration would need to be given as to which data could be used provide meaningful analyses and extreme caution should be applied when using prescribing data as a proxy measure. Further information on prescribing data is available at:

² <http://www.nhsggc.org.uk/media/232289/nhs-ggc-outreach-booklet.pdf>

http://www.nhsggc.org.uk/media/239143/nhsggc_ph_evaluation_of_the_renfrewshire_development_programme_2016-08.pdf

http://www.isdscotland.org/Health-Topics/Prescribing-and-Medicines/Prescribing-Datamarts/docs/PIS_fields_for_researchers_v5_eDRIS%20Guidance.pdf

1.3.3 District nursing, ISD / NHS Boards

Although at national level information on district nursing activity is not yet routinely reported, this is being collected and collated as part of the Community Health Activity Dataset. At local level NHSGGC have been making quarterly returns to ISD; these data should be available for analyses. Data include the number and type of contacts with district nursing service and nature of interventions.

http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Community-Health-Activity-Data-Project/District-Nursing/docs/20160420_DN_Dataset_Guidance_V1_2.pdf

In addition, within the Renfrew HSCP, local audit data has been identified that provides detailed information on those people within the HSCP area that had district nursing input and were identified by the district nursing team as having a palliative care need. These data do not contain a CHI number (or sufficient patient identifiers to allow CHI seeding) therefore cannot be linked at individual level to the previously described datasets. However, they do contain date of death and postcode of residence and it would therefore be possible to identify people from the proposed Renfrew cohort and present aggregate data from this source, including information about preferred place of care and death and whether these were met.

1.3.4 Community Mental Health Team Data, ISD / NHS Board

The collection and collation of data on community mental health team (CMHT) activity has recently begun as part of the Community Health Activity Dataset. These data are not yet reported at national level in Scotland. At local level, due to migration to a new information management system, submission of data to ISD from NHSGGC has not yet begun. In future however it should be possible to access data on CMHT activity and link these via CHI to the other datasets described. Further information on the CMHT dataset is available at:

http://www.isdscotland.org/Health%2DTopics/Health%2Dand%2DSocial%2DCommunity%2DCare/Community%2DHealth%2DActivity%2DData%2DProject/community%2Dmental%2Dhealth/docs/CMH-Dataset_Guidance-V1-2.pdf

1.3.5 Allied Health Professionals, ISD / NHS Boards

Information on use of services provided by allied health professionals is currently unavailable; a draft national dataset for AHP operational measures went to consultation in May 2017. It is anticipated that data collection will be individual level and episode based thereby facilitating future record linkage with other datasets. Further information is available at:

<http://www.isdscotland.org/Products-and-Services/Data-Definitions-and-References/Allied-Health-Professionals-National-Dataset/Operational-Measures.asp>

1.3.6 Marie Curie community nursing services, Marie Curie

Marie Curie provide a range of services across Scotland, commissioned by the territorial NHS boards for which they submit monthly service activity reports to the NHS Boards. Until recently these reports included a patient CHI number. Although this has been removed from routine service activity reports, this information is still collected by Marie Curie. It would therefore be possible to link data on Marie Curie activity in the community to other health and social care dataset within an appropriate information governance framework.

1.4 Hospice data

The level of data collected by independent hospices is unclear. Some hospices submit an SMR01 return to ISD relating to in-patient hospice admissions. Preliminary analysis of data from NHSGGC carried out by local health intelligence colleagues suggests under-reporting from one of the two local hospices in the Renfrew HSCP (The ACCORD and St. Vincent's). It is anticipated that this issue could be resolved through engagement with the hospice in question.

Despite the increasing importance of delivering community-based care, data on other services provided by the independent hospices, for example day care and home care is not systematically collected and collated at national level. In Renfrew HSCP these data are collated by individual hospices and the availability of a CHI number opens the possibility of linking these data to the other datasets identified.

1.5 Social care data

Local Authorities have agreed a minimum core dataset for collating data on social care provision and have begun submitting client level data to ISD. Client level data can be CHI seeded to allow linkage with other health datasets including the Scottish Morbidity Database and UCD. These will be available for analysis via the Source platform. Data will include the use of care homes, respite services, home care, meals on wheels, self-directed support and reablement. Crucially social care data includes information on whether a carers assessment was carried out and if the carer was receiving services; this is the only data source that we were able to identify that examined the needs of carers.

Data from Renfrew is, at the time of writing, undergoing final validation process prior to being submitted to ISD. It is anticipated that these data will be available for the proposed Renfrew Cohort Study. Further information on the Health and Social Care Data Integration and Intelligence project can be found here:

<http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Health-and-Social-Care-Integration/>

1.6 National Indicators: Quality Outcome Measure (QM) 10

The percentage of the last six months of life spent at home or in a community setting (QM 10) is a national indicator in Scotland's National Performance Framework (NPF). The indicator came into use in 2010 and is reported annually by ISD, overall for Scotland and at NHS territorial board and HSCP level. The measure aims to capture the delivery of patient centred care at home or in a homely setting as a proxy measure for preferred place of care.

The most recent data from ISD were published in 2016 and include data up to 31 March 2015. The method for calculating this measure recently changed; the number of bed days spent in any hospital (acute, community, psychiatric or long stay geriatric) is subtracted from the number of days in six months. It is important to note that hospice in-patient admissions may be included in SMR01 acute hospital returns. In addition, deaths by external causes, except those involving a fall, are excluded. Within the context of the proposed cohort study it would be possible to for these data to be linked at individual level to other health and social care datasets. Further information on this measure can be found here:

<https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-08-30/2016-08-30-End-of-Life-Report.pdf>

1.7 Other potential data sources identified that merit further exploration

1.7.1 Hospital and community complaints: DATIX, NHSGCC

Information on complaints routinely collected and collated and returned to ISD. At a local level these data are recorded on the DATIX system; a CHI number is routinely recorded which opens the possibility of linking these with other data on health and social care usage to provide some information, albeit crude, about patient experience. However the ethical issues around this would need to be carefully explored (the complaint about care may have been made by a proxy rather than the patient) and in order to protect patient confidentiality caution in reporting data would be required. It may be possible to examine aggregate data, for at NHS board or HSCP level by running a search for complaints with key words, 'end of life', 'palliative care', or 'terminal care'; it would be anticipated that this approach would underestimate the number of complaints given complaints may relate to communication issues or parking at the hospital when visiting a dying relative rather than being explicitly identified as relating to palliative and end of life care. Given the dearth of information about the experience of patients and their carers and the importance of getting end of life care right this may be an area worthy of further exploration, if not at a national, then at a local level to drive quality improvement. Further information about DATIX and hospital and community complaints can be found at:

<http://www.datix.co.uk/en/>

<http://www.ndc.scot.nhs.uk/National-Datasets/data.asp?ID=1&SubID=56>

1.7.2 Power of Attorney (PoA), Office of the Public Guardian

There has been growing interest in Scotland in increasing the number of people that make power of attorney (PoA) applications that outline their wishes should they become incapable of making decisions for themselves. The Office of the Public Guardian in Scotland process PoA registrations in addition to Intervention Orders (adults with incapacity) and Guardianship Orders (adults with incapacity where decision will be required on an on-going basis). They collect and collate data on all new registrations in Scotland and report aggregate anonymised data quarterly at NHS Boards and local authority level. The CHI number is not collected however it may be possible to CHI seed the data held by the Office of the Public Guardian based on available patient identifiers. This opens the possibility of linking PoA, Intervention Orders and Guardianship registrations to health and social care datasets. This would be a novel linkage. The potential for such a linkage within an appropriate information governance framework would need to be fully explored. On balance this was considered beyond the resource available for the Renfrew cohort study. Further information on the Office of the Public Guardian, PoA, Intervention Orders and Guardianships can be found here:

<http://www.publicguardian-scotland.gov.uk/power-of-attorney>

It is noteworthy that the Mental Welfare Commission for Scotland also collects, collates and reports detailed aggregate data at local authority and territorial NHS board level relating to their monitoring of the Adults with Incapacity Act. The Commission are members of 'The Sharing Intelligence for Health and Care Group'. Further information can be found at: <http://www.mwcscot.org.uk>

1.8 Significant information gaps

There are a number of significant information gaps, many of which have already been alluded to. These include:

- The identification and assessment of PELC needs in a range of settings;
- Information to support delivering care according to an individuals' preferences and priorities ;
 - Use of ACP and KIS: recording preferred place of care and death;
 - Recording the outcome of DNACPR discussions;
- Information about the quality of care;
 - Patient (and carer) reported outcomes;
- Information about specialist palliative care activity – hospice, hospital and community based;
- Information about the activity of AHP (consider oral health too);
- Information about bereavement services;

- Information about spiritual care / Chaplaincy³;
- Information about services provided by the third sector, including advocacy services; and
- Information on services purchased by people in receipt of self-directed payments.

Through local knowledge and expertise we have identified opportunities to use local data where national level data are lacking. For example in the Renfrew HSCP area we have identified local data that will allow us to examine the use of specialist palliative care services provided in hospice, hospital and community settings. This highlights the importance engaging with and securing the participation of key stakeholders at all stages of project development.

In other areas a local work around was identified however it was felt that this would not be deliverable within the resources available for the current project. The most notable example of this is the lack of data from primary care. It is anticipated that this gap will be addressed when the SPIRE project becomes fully operational in the near future.

It may also be possible to address the gap in the availability of information from the KIS data (including ACP) through SPIRE, although there are information governance issues that would need to be addressed first. At a local level we were able to identify rich data collected on a sub-group of people who were receiving district-nursing input and were identified as having a PELC need by the district nursing team. For this group we have detailed information about their preferences and priorities for care and how these were met. This group are unlikely to be representative of the wider cohort and unfortunately we are unable to link these data at individual level the other health and social care datasets but will be able to report aggregate data from the cohort.

Another potential work around identified by the PAG to obtain data on the use of ACP at local level would be to use the methodology developed by the Institute for Healthcare Improvement (IHI) in their White Paper 'Conversation Ready.' This would require detailed case review on a sample of people that died in a range of settings to identify whether their preferences for care and death were discussed,

³ In Renfrew HSCP we established that the chaplaincy service maintain a written record of referrals with minimal patient details; referrals to the services are generally made by telephone rather than electronically

recorded and ultimately met⁴. This offers a pragmatic solution to fill an important information deficit. Whilst there would be resources implications for undertaking such a study, it would provide an excellent opportunity to engage front line service providers with the project.

It is important to remain mindful of the potential impact of a number of national level work streams on the future availability of information to address some of the deficits identified. For example, the work on ACP and person centred outcomes being led by the iHub⁵.

A lack of patient centred outcome data is an important gap. Scotland strategic narrative for health and social care⁶ and more recently the CMO's Realistic Medicine⁷ focus on delivering care according to people's preferences and priorities yet data to assess how well we are performing in this area is lacking. The recently developed core suite of integration indicators will provide some data reported at NHS board and HSCP level, on the experiences of adults receiving care and support from a range of services, many of whom would be expected to have a PELC need.⁸ Much of the data populating these outcome measures will be derived from the Health & Care Experience Survey that reports data biannually at national, NHS board and HSCP level⁹. This survey also collects information on the experiences of carers.

⁴ McCutcheon Adams K, Kabcenell A, Little K, Sokol-Hessner L. *“Conversation Ready”: A Framework for Improving End-of-Life Care*. IHI White Paper. Cambridge, Massachusetts: Institute for Healthcare Improvement; 2015. Available online at:

<http://www.ihl.org/resources/Pages/IHIWhitePapers/ConversationReadyEndofLifeCare.aspx>

⁵ <http://ihub.scot>

⁶ A Route Map to the 2020 Vision for Health and Social Care. The Scottish Government, Edinburgh. 2011. Available at:

<http://www.gov.scot/Topics/Health/Policy/2020-Vision>

⁷ Chief Medical Officer for Scotland Annual Report 2015/16 Realising Realistic Medicine. The Scottish Government. 2015. Available online at:

<http://www.gov.scot/Publications/2017/02/3336/downloads#res-1>

⁸ Core Suite of Integration Indicators. The Scottish Government. 2015. Available at:

<http://www.gov.scot/Resource/0047/00475305.pdf>

⁹ Health & Care Experience Survey 2015/2016. The Scottish Government. Available at:

<http://www.gov.scot/Topics/Statistics/Browse/Health/GPPatientExperienceSurvey/HACE2015-16>

There is growing enthusiasm in Scotland to implement the VOICES¹⁰ study, a national survey of bereaved people carried out annually for the last 5 years in England to assess the quality of care and support for carers in the last 3 months of an adult's life. This would of course have resource implications; whilst there are plans to pilot the approach in selected localities in Scotland there are not currently plans for national roll out.

1.9 Key learning

Scotland has a rich tapestry of high quality routinely collected and collated data that can be used to create an individual level linked dataset to examine health and social care use in the last year of life. There are however significant gaps in the collection, collation and reporting of data at national and sub-national level.

A number of work streams are underway that will address many of the information deficits identified. The knowledge and expertise of local service providers and local health intelligence teams has made it possible to identify local data collected and collated for audit, service evaluation or quality improvement projects to fill some information gaps in the Renfrew HSCP area; we would anticipate this would be the same in other localities. It is important to note that locally collected data has not necessarily been through the rigorous quality assurance of nationally collated datasets and may contain limited information for secondary analysis. In addition data collection is unlikely to be standardised across localities thereby limiting the ability to compare and contrast service provision, activity or use across localities.

Finally, it is important to recognise that health and social care data are complex. Highly skilled analysts are required to explore the data. Information derived from routine data must be interpreted carefully, acknowledging the strengths and limitations of the available (and missing) data and framing findings within both the local context and the wider policy landscape.

¹⁰ ONS. National Survey of Bereaved People (VOICES). 2015. Available online at: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/england2015>

2. Creating a population profile

In this section we briefly explore the readily available national data sources could be used to create a population level profile for health and social care needs assessment of palliative and end of life care in any given locality. Data sources are considered across a number of broad categories: population demographics, life circumstances, carers, health status, service infrastructure and workforce, and other. Health and social care use and experiences of service users have been addressed in the preceding section and will not be revisited here.

2.1 Population demographics

2.1.1 Total population, age and sex structure of the population

The NRS publish mid-year population estimates describing the total population, and the age and sex structure of the population. Data are at national, administrative, Scottish Council and NHS Board level. The latest population estimates for 2016 can be found here:

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-estimates/mid-year-population-estimates/mid-2016/list-of-tables>

2.1.2 Population projections, 2014 - 2039

The NRS produce population projections. These data can be used to estimate the predicted change in total population and the age and sex structure of the population in a locality over time. Projections are reported at the national, Scottish Council, NHS Board, Strategic Development Plan and National Park area level, overall and according to age (single year) and sex. Population projections are based on a range of assumptions around fertility, mortality, immigration and emigration; they should therefore be interpreted with caution. Further information on population projections and their uses and limitations can be found here:

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections>
<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/uses-and-limitations-of-population-projections>

2.1.3 Ethnicity

Data on ethnicity, identity, language spoken and religion are collected in the Census, which collects information on the entire population every ten years. These are available at national, local authority and NHS board level. The latest data from the 2011 Census is available online at:

<http://www.scotlandscensus.gov.uk/ethnicity-identity-language-and-religion>

2.2 Life circumstances

2.2.1 Multiple Deprivation

The Scottish Index of Multiple Deprivation (SIMD) is the Scottish Government's tool for identifying areas of deprivation and measuring health inequalities. It consists of 38 indicators across seven domains (income, employment, health, education, skills and training, housing, geographical access to services and crime). Each domain contributes to an overall SIMD score for each of 6,976 data zones, small geographical areas. Scores are then ranked from the most to the least deprived. SIMD is reported at national, NHS board and local authority level.

The SIMD can be used in a number of different ways to examine multiple deprivation. Commonly data are presented in quintiles from the most to the least deprived areas; these can be stratified according to age to examine the percentage of elderly (aged 65 years and over) living in the most deprived quintile. Income deprivation is often used as a proxy measure of multiple deprivation; SIMD16 measures the percentage people (adults and their dependants) in receipt of income support, employment and support allowance, job seekers allowance, guaranteed pensions credits and child and working tax credits. Sometimes the 'local' share of the most deprived 20% is reported, calculated by dividing the number of data zones in an area that are classified as being in the most deprived 20% according to SIMD16 by the total number of data zones in an area. SIMD16 also provides an opportunity to examine access deprivation, capturing the financial cost, time and inconvenience of having to travel to access basic services. Further information on the SIMD16 can be found at:

<http://www.gov.scot/Topics/Statistics/SIMD>

It is recognised that SIMD is less efficient at measuring deprivation in rural areas. Further information on this topic is available here:

<http://www.scotpho.org.uk/downloads/scotphoreports/scotpho140109-simd-identifyingdeprivedindividuals.pdf>

2.2.2 Urban Rural Classification

Rural areas are often less densely populated than urban areas and contain a higher proportion of elderly people. Life expectancy in rural areas is greater than urban areas, which may be attributable to migration in later life. People living in rural areas often experience poverty, social exclusion and poor access to services. The Scottish Government has developed an Urban Rural Classification Scottish Government classification that combines both population data (from NRS) and accessibility measures. These data are reported at national, NHS board and local authority level and can be used to quantify the percentage of elderly people (aged 65 years and over) living in rural areas. Further information is available from:

<http://www.gov.scot/Topics/Statistics/About/Methodology/UrbanRuralClassification>

2.2.3 Dependency ratio

The dependency ratio provides a summary measure of the relative age structure of the population calculated as the number of children (<16 years old) and old people (state pension age and over) per 100 people of working age. NRS report information on the current and projected (2014 – 2039) dependency ratios can be found here:

<https://www.nrscotland.gov.uk/files/statistics/population-projections/2014-based/pp14.pdf>

2.2.4 Households

Information on the current and projected composition of households in Scotland is available from a number of sources. Household composition has important implications for the availability of informal carers to support people living at home. Information at national, NHS board and local authority level on the number and composition of households, including the proportion of single adult households is collected in the Census. The latest data from the 2011 Census is available from:

<http://www.scotlandscensus.gov.uk/housing-and-accommodation>

Additional analyses of data from the 2011 Census have examined household composition according to age group, focusing on people aged 65 years and over. Further information can be found here:

http://www.scotlandscensus.gov.uk/documents/analytical_reports/HH%20report.pdf

NRS have produced household projections for Scotland reported at national and Scottish Council level for the number, type and age of head of household (2014 – 2039). Further information can be found here:

<https://www.nrscotland.gov.uk/files//statistics/household-projections/2014-based/2014-based-household-projections.pdf>

The Scottish Household Conditions Survey (SHCS) is an annual survey of domestic dwellings in Scotland. Data available, at national and local authority level, include the proportion of households that have an inhabitant who is long term sick or disabled, receives care services or the premises have been adapted to meet the needs of the inhabitant. Additional data related to fuel poverty has been collected in the latest survey, which published data from 2011-2013. Further information is available at:

<http://www.gov.scot/Topics/Statistics/SHCS>

Elements of The Scottish Household Conditions Survey were integrated into the Scottish Household Survey (SHS) in 2012. The SHS is a continuous survey that samples people living in private residences to provide information on a range of issues relating to housing, social justice and transportation to inform local and national policy. Information on the composition of households, income and employment, self-assessed health and disability and carer responsibilities is

collected, collated and published at national and local authority level annually. Further information is available from:

<http://www.gov.scot/Topics/Statistics/16002/SurveyOverview/>

2.2.5 Economic Activity

Information on eligibility for and payment of a range of benefits including attendance allowance, carers allowance, disability living allowance and personal independence payments is collected, collated and reported by the Department for Work and Pensions (DWP), available at national and Scottish Council area level. These data can be accessed via the following link:

<https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml>

Information on the number of people that are economically active is collected in the Census. Information from the 2011 Census is available here:

<http://www.scotlandscensus.gov.uk/labour-market>

As previously noted information on income and employment is available from the SHS:

<http://www.gov.scot/Topics/Statistics/16002/SurveyOverview/>

2.3 Carers

A range of information is available relating to informal carers. A 2015 overview on Scotland's Carers published by the Scottish Government is available here:

<http://www.gov.scot/Resource/0047/00473691.pdf>

Information on the provision of unpaid care and the number of hours of unpaid care is collected in the Census. Data from the 2011 Census can be found here:

<http://www.scotlandscensus.gov.uk/variables-classification/provision-unpaid-care>

The Scottish Health Survey (SHeS) is a continuous survey of a sample of private households in Scotland to provide a detailed picture of health and well-being in Scotland. The survey includes a number of questions about the level of unpaid care provided, the length of time a person has been caring and the number of hours a week spent caring, the impact on employment and the level of support carers received. These data are available at national and NHS board level. Information from the 2015 SHeS can be found in the supplementary tables here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey/Publications/Supplementary2015>

As previously noted information on receipt of carers allowance is available from the DWP. DWP data can be found here:

<https://stat-xplore.dwp.gov.uk/webapi/jsf/login.xhtml>

Information on the experiences of carers is now collected in the bi-annual Scottish Health & Care Experience Survey that reports data at national, NHS board and HSCP level. Additional information is available here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/GPPatientExperienceSurvey/HACE2015-16>

2.4 Health Status

2.4.1 Life expectancy

Data on life expectancy, according to sex and age group, is published by NRS at national, health board, Scottish Council levels and by special area. Further information can be found here:

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/life-expectancy>

2.4.2 Healthy Life expectancy

Healthy life expectancy (HLE) is an estimate of how long a person might live in a healthy state and is considered a useful summary measure of the overall health of the population. Data on HLE is published by the Office of National Statistics although a useful summary is available on the ScotPHO website. Further information on both is available at the following weblinks:

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandlifeexpectancies/publications>

<http://www.scotpho.org.uk/population-dynamics/healthy-life-expectancy/data/data-introduction>

<http://www.scotpho.org.uk/downloads/hle/HLE-technical-paper-2016-v10.pdf>

2.4.3 Health and health related behaviours

Information about the health and health related behaviours of people in Scotland are collected in a range of surveys including the SHeS, the SHS and the Census.

2.4.3.1 Lifestyle factors: smoking, alcohol, diet and exercise

Given many chronic conditions are attributable in part of lifestyle factors such as smoking, drinking alcohol, sedentary lifestyle and diet there may be interest in reporting the prevalence of these health related behaviours in HSCNA to inform future service planning. The SHeS survey also contains information on clinical risk factors such as obesity and hypertension. The SHeS provides perhaps the most detailed information on self-reported health related behaviours and clinical risk factors. Information from the most recently, 2015 SHeS survey can be found here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey>

2.4.3.2 Self-reported health

Categorical data on self-reported health is collected, collated and reported in the SHeS, SHS and Census. The latest information from each survey is available here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey>

<http://www.gov.scot/Publications/2016/09/7673/2>

<http://www.scotlandscensus.gov.uk/health>

2.4.3.3 Mental health and wellbeing

The SHeS collects, collates and reports information on mental health and wellbeing through the Warwick-Edinburgh Mental Health Wellbeing Scale (WEMWBS). Information from the latest SHeS survey is available here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey>

2.4.3.4 Long term conditions and disability

Information on long-term conditions and disability is collected in a range of surveys including the SHeS, SHS and Census. Further information on these can be found here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey>

<http://www.gov.scot/Publications/2016/09/7673/2>

<http://www.scotlandscensus.gov.uk/health>

2.4.3.5 Adults with Incapacity

The Mental Welfare Commission published data annually at national, NHS board and local authority level, relating to the adults with incapacity act including guardianship orders. Further information can be found at: <http://www.mwcscot.org.uk>

2.4.3.6 Power of Attorney

The Office of the Public Guardian in Scotland process PoA registrations in addition to Intervention Orders (adults with incapacity) and Guardianship Orders (adults with incapacity where decision will be required on an on-going basis). They collect and collate data on all new registrations in Scotland and report aggregate anonymised data quarterly at NHS Boards and local authority level. Further information on the Office of the Public Guardian, PoA, Intervention Orders and Guardianships can be found here:

<http://www.publicguardian-scotland.gov.uk/power-of-attorney>

2.4.3.7 Disease estimates

The National Burden of Disease, Injuries and Risk Factors Study, a collaboration between ScotPHO, ISD and NHS Health Scotland using the Global Burden of Disease Methodology, will shortly report its preliminary findings, providing very detailed information on the incidence, prevalence and impact of a range of diseases, injuries and risk factors in Scotland by age, sex, deprivation and NHS board. The study will include disease projections and will provide valuable information to inform the design and delivery of health and social care services. Further information on the study is available here:

<http://www.scotpho.org.uk/comparative-health/burden-of-disease/overview>

Data from the SHeS can be used to provide prevalence estimates of disease in Scotland. Further information is available here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/scottish-health-survey>

Previously prevalence estimates for a range of diseases were available from the Quality Outcomes Framework (QoF) in primary care. The final QoF publication provides data from 2015-16 and is available here:

<http://www.isdscotland.org/health-Topics/General-Practice/Quality-And-Outcomes-Framework/>

Use of health and social care services can provide a proxy estimate of disease prevalence and in some cases incidence. Given detailed exploration of health and social care data in previous sections with will not be revisited here. However it is worth noting two tools that have not previously been discussed. Firstly, the SPARRA tool (Scottish Patients at Risk of Readmission and Admission), which predicts an individual's at risk of being admitted to hospital as an emergency inpatient within the next year. SPARRA scores range from 1 to 99%; a score of 50 suggests a 1 in 2 chance of emergency admission to hospital in the coming year. Further information on the SPARRA tool is available from:

<http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA/>

The second tool is the Indicator of Relative Need (IoRN) is a standardised measure of functional dependency collected by front line staff across Scotland. This has been used to describe the changing functional needs and dependency of people living in care homes in Scotland. Further information on the IoRN can be found here:

http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Dependency-Relative-Needs/In-the-Community/docs/IoRN%20Questions%20Jan16_updated%2004April2017.pdf
<https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2017-02-28/2017-02-28-The-changing-functional-needs-and-dependency-of-people-living-in-care-homes-Summary.pdf>

Additional information on population estimates of disease may be available from disease specific registries, reports and peer-reviewed publications. In some areas disease projections have been produced, for example cancer incidence projections (<http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/Incidence-Projections/>) or the projected rates for dementia diagnoses in Scotland (<http://www.gov.scot/Publications/2016/12/9363/1>). Other HSCNA may also have collated data from a range of different sources, for example the ScotPHN Older Persons Needs Assessment available here: <http://www.scotphn.net/projects/older-people-health-and-social-care-needs-assessment/health-and-social-care-needs-assessment-of-older-people-reports/>

2.4.3.8 Mortality data

NRS publish detailed information on the number of deaths in Scotland according to age, sex and ethnic group, annually at national level and by administrative area. Information on cause of death is examined by age and sex at national level and administrative area. Further information can be found here:

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/deaths>

The projected number of deaths (2014-2039) at national level is also available here:

<https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/population/population-projections/population-projections-scotland/2014-based/list-of-tables>

2.5 Service Infrastructure and workforce

2.5.1 NHS Continuing Care

Information on the number of people in NHS continuing care beds according to age, sex and category of care at national, territorial health board and local authority level is published in an annual census report by ISD. Further information is available from: <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/NHS-Continuing-Care/>

2.5.2 Scottish Care Home Census

ISD collect, collate and publish information for the annual Scottish Care Home Census which collects information about the number of care home places and residents (admissions, discharges and deaths), source of admission, financial support and characteristics of residents in adults (18 years and over) care homes registered with the Care Inspectorate in Scotland. Data are available at national and local authority level. The latest data from 2016 can be found here:

<https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-10-25/2016-10-25-CHCensus-Summary.pdf>

2.5.3 The Scottish Social Care Survey

Since 2013, The Scottish Social Care Survey has collected, collated and published detailed information on social care services provided or purchased by all 32 local authorities in Scotland. In addition data on self-directed support is also available. Information includes the type of services received and the characteristics of clients and is presented at national and local authority level. The latest information from the 2016 report is available here:

<http://www.gov.scot/Publications/2016/11/8311/downloads#res-1>

Further information relating to social care can be found in the Scottish Governments quarterly survey of local authority eligibility and waiting times for social care, which also contains information on care homes residents people receiving free personal and nursing care. More information on these resources can be found here:

<http://www.gov.scot/Topics/Statistics/Browse/Health/Data/QuarterlySurvey#top>

2.5.4 Workforce

ISD collect, collate and report quarterly workforce data for a range of NHS employees working across specialties and disciplines at national and NHS board level. Information on for example clinical nurse specialists is broken down by specialty, contract type, gender, whole time equivalent and head count. Information on the number of palliative medicine consultants (WTE and head count) across Scotland and by NHS Board area is also available. Further information can be found here:

<http://www.isdscotland.org/Health-Topics/workforce/Publications/data-tables2017.asp?id=1870#1870>

Information on the specialist palliative care workforce within the independent hospices is not nationally collated although may be available on request from individual providers.

Detailed information on the head count and WTE number of general practitioners, registered nurses and other clinical staff in primary care and Out of Hours GP services is collected in the primary care workforce survey. These data are reported nationally and at NHS Board level but can on request be accessed at HSCP level. The last information from the 2015 survey can be accessed here:

http://www.isdscotland.org/Health-Topics/General-Practice/Workforce-and-Practice-Populations/Workforce/national_primary_care_workforce_survey.asp

Finally detailed information is collected and collated on the social care workforce in Scotland in the Scottish Social Services Sector Report. The latest report from 2015 can be found here:

<http://data.sssc.uk.com/data-publications/22-workforce-data-report/128-scottish-social-service-sector-report-on-2015-workforce-data>

There is also an annual report published on the Mental Health Officer workforce in Scotland. The latest, 2015 report, can be found here:

<http://data.sssc.uk.com/data-publications/23-mental-health-officers-reports/127-mental-health-officers-scotland-report-2015>

2.5.5 Other

2.5.5.1 National Indicators and Benchmarking tools

A range of national indicators and benchmarking tools are available that provide valuable data summarising key measures in relation to health and social care in Scotland. A national indicator for palliative care (QM10) published on annually at national, health board, and local authority level is available describing the percentage of the last six months of life spent at home or in a community setting.

<https://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/Publications/2016-08-30/2016-08-30-End-of-Life-Report.pdf>

In addition a core suite of indicators for integration examining a range of health and social care measures is available. Importantly these include information on patient and carer experience for the Health & Care Experience Survey. Further information is available from:

<http://www.gov.scot/Resource/0047/00475305.pdf>

The local government benchmarking framework also includes indicators on adult social care. Further information is available from:

<http://www.improvementservice.org.uk/benchmarking/>

2.5.6 General resources

2.5.6.1 ScotPHO

The ScotPHO website provides a rich web-based resource that brings together information from a range of sources in a single site and helpfully contextualising data. In 2015 ScotPHO created a Health and Well-being online profiles tool that collates information on indicators from a range of sources. Data including population demographics, housing, employment, income and benefits and health outcomes, are collated at national, NHS board, local authority and intermediate zone level. An older persons profile has also been created. Further information is available from:

<http://www.scotpho.org.uk/comparative-health/profiles/online-profiles-tool>

3. Renfrew HSCP Data Analysis Plan

The section that follows describes an analysis plan developed following the scoping exercise to identify suitable sources of routinely available data to create an individual level linked dataset for a cohort of people from the Renfrew HSCP area to examine health and social care use in the last year of life.

Objectives To describe health and social care use in the last year of life.

Design Population based retrospective cohort study using routinely linked administrative data.

Population All adults (aged 18 years and over) from the Renfrewshire HSCP area that died between 1 January 2016 and 31 December 2016; residence determined by usual place of residence recorded on death certificate.¹¹

Data Sources

- Death Certificate Data (NRS)
- SMR01 Acute hospital admissions (ISD)
- SMR04 Psychiatric hospital admissions (ISD)
- Out-patient attendances, Trak Care (NHS Greater Glasgow and Clyde)
- Day hospital attendances, Trak Care (NHS Greater Glasgow and Clyde)
- Delayed discharges, Eddisson (NHS Greater Glasgow and Clyde)
- Hospital specialist palliative care team (local audit data)
- Unscheduled care: NHS24, SAS, Emergency attendances (ISD)
- GP Out of Hours care (ISD)
- Community district nursing (ISD) & local audit data (Renfrew HSCP)
- Marie Curie community nursing data
- Hospice data (ACCORD & St Vincent's Hospices)
- Social care data (Renfrew HSCP)
- Community prescribing data (ISD)

¹¹ The cohort will include deaths from all causes. The use of death certification to identify people with a PELC need may miss individuals that died from an unrelated external cause who in life had a PELC need. For example, a person with terminal cancer may die in a road traffic accident. Unless their terminal cancer diagnosis directly contributed to their death, it would not be recorded in death certification.

3.1 Overview of analysis plan

Initial analyses will quantify the overall use of health and social care in the last year of life, before examining the pattern of use by months to death. An estimate of population level PELC need based on analysis of routine data will be calculated and we will explore how this could be refined in our cohort.

Further analyses could compare and contrast health and social care use in the last year of life by key characteristics such as age group, sex, ethnicity, socioeconomic deprivation, place and cause of death with the aim of identifying those factors that are independently associated with use.

Although beyond the scope of the current project, future analyses could examine in detail health and social care use according to disease specific groups, for example people dying from health failure or liver disease, or the elderly (aged 75 years and over) and include economic analyses to estimate the cost of health and social care use in the last year of life.

3.2 Analysis plan

3.2.1 Death certificate data

- Total number of deaths
- Number (%) of deaths according to sex
- Mean (SD), median (IQR) and range of age at death age (years)
- Number (%) deaths according to age group at death (years)
 - <65, 65 – 74, 75 - 84, ≥85 years
- Number (%) deaths according to SIMD quintile
- Number (%) deaths according to ethnicity
 - White, BAME¹²
- Number (%) deaths according to marital status¹³
 - Married, single, widowed, divorced
- Number (%) deaths according to place of death¹⁴
 - Home, care home, hospice, hospital, other
- Number (%) of deaths in usual place of residence (DiUPR)
 - Number (%) of care home residents who die in a care home
- Number (%) of deaths according to cause (Tables 1 and 2)
 - Underlying cause of death, then 'any mention' on death certificate
- Number (%) of deaths deemed to be 'unexpected'¹⁵

¹² Unclear how robustly data on ethnicity recorded. Need to ensure that anonymity preserved which may necessitate just 2 categories, white and BAME

¹³ Use definitions developed by ISD in reporting place of death for cancer statistics

¹⁴ Use definitions developed by ISD in reporting place of death for cancer statistics

¹⁵ Methodology developed by Public Health England using underlying cause of death for a range of conditions outlined in Table 3.

- Crude mortality rate
- Age and sex specific mortality rates
 - Age groups: <65, 65 - 74, 75 - 84, ≥85 years
- DiUPR summarised according to age group, sex, SIMD quintile, ethnicity (white vs. BAME), cause of death (cancer vs. non-cancer)¹⁶
- Cause of death (cancer vs. non-cancer) summarised according to age group, sex, SIMD quintile and ethnicity (white vs. BAME)

3.2.2 Estimating PELC need at population level (the Murtagh approach¹⁷)

Lower estimate: Underlying cause of death recorded as one of the specified diagnoses (Table 4)

Mid (lower): Underlying cause of death recorded as one of the specified diagnoses (Table 4), PLUS deaths where Alzheimer's Disease, Dementia or Senility (F01, F03, G30, R54) or Renal Disease (N17, N18, N28, I12, I13) contributed to death

Mid (Upper): Specified diagnoses (Table 4) recorded as underlying OR contributory cause of death

Max estimate: All causes of death except those where underlying cause of death was one of the following ICD10 codes: pregnancy, childbirth or puerperium (O00-O99); originating in the perinatal period (P00-P96); resulting from injury, poisoning and other similar causes (S00-T98) and those resulting from external causes (V01-Y98)

3.2.3 Investigating those that died of external cause (underlying cause of death)

- Number (%) that had ≥1 of the diagnoses listed in Table 2 *anywhere* on their death certificate
- Number (%) that had ≥1 of the diagnoses listed in Table 2 in any diagnostic position in any episode of care in a hospitalisation during the last year of life
- Number (%) that had ≥1 co-morbidity¹⁸ or frailty indicator¹⁹
- Number (%) that died in a hospital, hospice or care home
- Of those that died in a hospital or hospice, mean (SD), median (IQR) and range of time (days) from admission (days) until death
- Number (%) that had none of the above

¹⁶ Cancer denoted by underlying cause of death ICDO 10 coded C00 – C97; non-cancer includes all other underlying causes of death; on inspection of the data it may be possible to analyse 4 categories: cancer (C00-C97), Respiratory disease (J00-J99), Circulatory disease (All I codes) and 'other' denoting all other groups.

¹⁷ Murtagh *et al.* How Many People Need Palliative Care? A study developing and comparing methods for population-based estimates. *Pall Med.* 2014;28(1):49-58.

<http://journals.sagepub.com/doi/10.1177/0269216313489367>

¹⁸ Co-morbidities as recorded in Source (Table 4)

¹⁹ Approach developed by Poots *et al* and currently being validated in Scotland.

<http://www.acutemedicine.org.uk/wp-content/uploads/2016/09/R29.pdf>

- Distribution of external causes of death (see Table 5)

3.3 Hospital-based care

3.3.1 Co-morbidities derived from SMR01/SMR04

- Summary of co-morbidities using hospitalisation data, N (%)²⁰
- Number (%) of people with frailty indicators²¹
- Mean (SD), median (IQR) and range of number of comorbidities per person
- Number (%) of people with multi-morbidity (≥ 2 co-morbidities)²²

3.3.2 Hospitalisations

Unless otherwise indicated analyses reported overall, then according to months to death. Subsequent analyses to explore health and social care use stratified by sex, age group, SIMD quintile, ethnicity (White vs. BAME) and cause of death (cancer vs. non).

3.3.2.1 All Hospitalisations²³

- Total number of hospital admissions accounted for by cohort
- Crude rate of hospitalisation
- Total number (%) of people with ≥ 1 hospitalisation
- Mean (SD), median (IQR) and range of hospital admissions per person
- Of those with ≥ 1 hospitalisation, mean (SD), median (IQR) and range of hospital admissions per person
- Total number of bed days accounted for by cohort
- Mean (SD), median (IQR) and range of bed days per person
- Of those with ≥ 1 hospitalisation, mean (SD), median (IQR) and range of bed days per person
- Of those with ≥ 1 hospitalisation, mean (SD), median (IQR) and range of bed days per admission
- Number (proportion) of people that underwent one or more OPCS4 coded procedure or intervention
- Number (proportion) of hospital admissions in which one or more OPCS4 coded procedure or intervention was recorded
- Total number of procedures or interventions undertaken during hospital admissions
- Mean (SD), median (IQR) and range of number of procedures or interventions undertaken per person

²⁰ Co-morbidities as recorded in Source (Table 4)

²¹ Approach developed by Poots *et al* and currently being validated in Scotland.

<http://www.acutemedicine.org.uk/wp-content/uploads/2016/09/R29.pdf>

²² Co-morbidities as recorded in Source (Table 4)

²³ All SMR01/SMR04 admission to hospital (emergency or elective); a hospital admissions denoted by a completed continuous in-patient stay. Hospice data should be removed from SMR01 and analysed separately.

- Of those who underwent one or more procedure or intervention, mean (SD), median (IQR) and range of number of procedures undertaken
- Summary of OPCS4 coded procedures or interventions undertaken in the last year of life

3.3.2.2 Repeat analyses stratified by the following admission types:

- Continuing care/geriatric long stay bed only
- Day cases only
- SMR04 Hospitalisations only²⁴
- Emergency admissions only
- Elective admissions only

3.3.2.3 Additional analyses: emergency admissions only

- Day of hospital admission, N (%)
- Summary of time of hospital admission (hourly increments)
- Number (%) of all admissions that occur in the out of hours period
 - between 18:00 and 08:00 on a week day, at the weekend (18:00 Friday to 08:00 Monday) or a Public Holiday²⁵
- Number (%) of all
- Summary of location 'admitted from' listed in index episode of CIS (N, %)
- Summary of location 'discharged to' listed in index episode of CIS (N, %)
- Summary of principal diagnosis listed in index / last episode of CIS (N, %)²⁶
- Number (%) of people with ≥ 3 admissions to hospital in the last year of life
- Proportion of all hospital admissions accounted for by those that had ≥ 3 admissions to hospital in the last year of life
- Number (%) of potentially preventable admissions (PPA) to hospital ²⁷
- Number of people (%) who experienced ≥ 1 PPA⁵
- Mean (SD), median (IQR) and range of PPA per person
- Total number of bed days accounted for by PPA
- Number (%) of people admitted to hospital from home that are discharged to a care home²⁸

²⁴ SMR04 hospitalisations can include periods where patients are out on pass and may differ significantly from SMR01 hospitalisations therefore these should be explored separately. Need to consider examining both SMR04 admissions and discharges; patients may have extended stays, for example over 1 year, therefore it is important to ensure that these people are captured.

²⁵ Identify these admissions from the unscheduled care datamart

²⁶ Need to explore data to determine degree of correlation between principal diagnosis in first and last episode of CIS before deciding which to use for analyses

²⁷ For SMR01 emergency admissions only <http://www.isdscotland.org/Products-and-Services/Discovery/Metadata/PotentiallyPreventableAdmissions.pdf?09:12:12>

²⁸ <http://www.gov.scot/Resource/0047/00475305.pdf>

3.3.2.4 Potential Markers of 'aggressive' treatment²⁹

- Number (%) of people admitted to hospital within the last 7 days of life
- Number (%) of people admitted to hospital within the last 30 days of life
- Number (%) of people that spent more than 14 of last 30 days of life in hospital
- Number (%) of people that spent ≥ 30 days in hospital in the last year of life
- Number (%) of people that were admitted to ICU/HDU/CCU in any episode of care in a completed CIS in the last 7 days of life
- Number (%) of people that were admitted to ICU/HDU/CCU in any episode of care in a completed CIS in the last 30 days of life
- Number (%) of people that were treated with invasive ventilation (OPCS4 code E85.1) during any episode of care in a completed CIS in the last 7 days of life
- Number (%) of people that were treated with invasive ventilation (OPCS4 code E85.1) during any episode of care in a completed CIS in the last 30 days of life
- Number (%) of patients with an underlying diagnosis of cancer who had chemotherapy (OPCS code X70-X73) in the last 14 days of life
- Number (%) of patients with an underlying diagnosis of cancer who had chemotherapy (OPCS code X70-X73) in the last 30 days of life
- Number (%) of admissions that led to readmission within:
 - 7 days of discharge
 - 28 days of discharge
- Number (%) of admissions to hospital during which the patient died
- For terminal admissions to hospital:
 - Summary location 'admitted from' (N, %)
 - Mean (SD), median (IQR) and range of time (days) from admission to death
 - Number (%) that die within 48 hours of admission
 - Number (%) that die within 7 days of admission
 - Number (%) that die following an admission of 8 days or longer

3.3.2.5 Repeat markers of aggressive treatment analyses limited according to whether frailty indicators were present (if numbers allow)⁵

²⁹ Langton *et al.* Retrospective studies of end of life resource utilisation and costs in cancer care using health administrative data: a systematic review. *Pall Med.* 2014. DOI: 10.1177/0269216314533813; analyses reported overall only

3.3.3 Delayed discharges (EDISON, NHSGGC)

- Number (%) of hospitalisations identified as a delayed discharge
- Number (%) of people that experienced ≥ 1 delayed discharged
- Reason for delayed discharge, N (%)
- Total number of additional bed days accounted for by delayed discharges
- Number (%) of hospitalisations identified as delayed discharge during which the person died in hospital

3.3.4 Out-patient attendances (TRAKCare, NHSGGC)

- Number (%) of people who had an out-patient appointment (any specialty or discipline) in the last year of life
- Total number of out-patient appointments (any specialty or discipline)
- Mean (SD), median (IQR) and range of number of out-patient appointments (any specialty or discipline) per person
- Of those that attended ≥ 1 out-patient appointment, mean (SD), median (IQR) and range of number of out-patient appointments per person (any specialty or discipline)
- Of those that attended ≥ 1 out-patient appointment, mean (SD), median (IQR) and range of number of different specialties or disciplines involved in out-patient care per person

3.3.5 Day hospital attendances (TRAKCare, NHSGGC)

- Number (%) of people that had ≥ 1 day hospital attendance
- Mean (SD), median (IQR) and range of day hospital attendances per person
- Of those with ≥ 1 day hospital attendance, mean (SD), median (IQR) and range of day hospital attendances per person

3.3.6 Local audit data on activity of hospital specialist palliative care team

- Number (%) of people that were seen by hospital based specialist palliative care team during last year of life
- Of those seen by hospital based specialist palliative care team during the last year of life, mean (SD) median (IQR) and range of time (days) from first review by hospital based specialist palliative care team to death
- Of those that died during an admission to hospital, number (%) that received input from hospital-based specialist palliative care team during terminal admission

3.3.7 Unscheduled care: NHS24, SAS, A&E, OOH Primary Care (UCD, ISD)

- Total number of NHS24 contacts
- Crude rate of NHS24 contacts
- Number (%) of people with ≥ 1 NHS24 contact
- Mean (SD), median (IQR) and range of number of NHS24 contacts per person
- Of those with ≥ 1 NHS24 contact, mean (SD), median (IQR) and range of number of NHS24 contacts per person
- Summary of outcome of NHS24 contact (N, %)
- Total number of OOH primary care (PC) contacts

- Crude rate of OOH PC contacts
- Number (%) of people that had ≥ 1 OOH PC contact
- Mean (SD), median (IQR) and range of OOH PC contacts per person
- Of those with ≥ 1 GP contact, mean (SD), median (IQR) and range of number of OOH PC contacts per person
- Number (%) of all OOH PC contacts in which ECS was accessed
- Number (%) of all OOH PC contacts in which KIS was accessed
- Summary of outcome (N, %) of OOH PC contact
- Total number of SAS contacts
- Crude rate of SAS contacts
- Number (%) of people who had ≥ 1 SAS contact
- Mean (SD), median (IQR) and range of SAS contacts per person
- Of those with ≥ 1 SAS contact, mean (SD), median (IQR) and range of SAS contacts per person
- Number (%) of deaths in transit
- Total number of A&E attendances accounted for by cohort
- Crude rate of A&E attendances
- Number (%) of people with ≥ 1 A&E
- Mean (SD), median (IQR) and range of number of A&E per person
- Of those people with ≥ 1 emergency attendance, mean (SD), median (IQR) and range of number of A&E per person
- Number (%) of A&E attendances that led to admission (discharge type 02)
- Number (%) of deaths in occurred in the emergency care setting (discharge type 05A/05B)
- Summary of continuous unscheduled care patient journey (N, % of contacts accounting for each pathway)
- Number (%) of contacts by day, overall then according to service used
 - NHS24, OOH PC, SAS, A&E
- Number (%) of contacts by time of day (hourly increments) on week days³⁰, overall then according to service used
 - NHS24, OOH PC, SAS, A&E
- Number (%) of contacts by time of day (hourly increments) on weekends³¹, overall then according to service used
 - NHS24, OOH PC, SAS, A&E

3.4 Community-based care

Unless otherwise indicated analyses reported overall, then according to months to death. Subsequent analyses to explore health and social care use stratified by sex, age group, SIMD quintile, ethnicity (White vs. BAME) and cause of death (cancer vs. non)

3.4.1 Community prescribing data

- Mean (SD), median (IQR) and range of number of different medications prescribed per person³²

³⁰ Week days, 08:00 Monday through 18:00 Friday

³¹ Weekends 18:00 Friday through 08:00 Monday

- Number (%) of people prescribed any opiate (codeine, dihydrocodeine, tramadol, nefopam, morphine, diamorphine, oxycodone, fentanyl, alfentanil methadone)
- Number (%) of people prescribed one or more of the following injectable (S/C) medications: Analgesia (morphine or diamorphine), Anxiolytic (midazolam), Anti-secretory (hyoscine), Anti-emetic (levomeprimazine) or anti-psychotic (haloperidol)³³
- Of those prescribed one or more of the above injectable S/C medications, number (%) that died at home
- Number (%) of people prescribed any statin medication by months to death only (atorvastatin, fluvastatin, pravastatin, rosuvastatin, or simvastatin)

3.4.2 District-nursing data

- Number (%) of people that had ≥ 1 contact with district nurse
- Of those that received district nursing input, mean (SD), median (IQR) and range of time (days) from first contact with to death³⁴
- Of those that had district nursing contact, mean (SD), median (IQR) and range of number of district nursing contacts (any type) per person
- Total number of district nursing contacts accounted for by cohort
- Total number of district nursing contacts accounted for by cohort according to type of contact: direct, indirect or other
- Total district nursing time (minutes) accounted for by cohort
- Of those that had ≥ 1 district nursing contact, mean (SD), median (IQR) and range of time spent by district nurse per person
- Of those that had ≥ 1 district nursing contact, mean (SD), median (IQR) and range of time spent by district nurse per person according to type of contact

Of those that had ≥ 1 district nursing contact and were identified by the local district nursing team as having a palliative care need³⁵:

- Number (%) that had an eKIS
- Number (%) that had an advanced care plan in place
- Number (%) that had a guardianship in place
- Number (%) that had a DNACPR documented
- Number (%) that had RNVoED documented
- Number (%) that had JiC Box in place
- Number (%) that had a community palliative care kardex in place
- Number (%) that had an individual end of life care plan in place
- Number (%) that had their PPC met

³² Attempting to capture overall burden of medication not changes in dose of a medication.

³³ Prescription of injectables a proxy for planning death at home

³⁴ Denoted by date care first began in first episode of care

³⁵ These data are available from HSCP – we can identify individuals from our cohort but it is not possible to link them with other data at individual level. These analyses presented overall for the entire cohort only

3.4.3 Marie Curie community nursing

- Number (%) of people that received input from Marie Curie community services in the last year of life
- Of those that received input from Marie Curie services in the last year of life, mean (SD), median (IQR) and range of time (days) from first contact with Marie Curie community services until death
- Number (%) of people that accessed overnight visits provided by Marie Curie
- Of those that received overnight visits, mean (SD), median (IQR) and range of number of overnight visits provided by Marie Curie per person
- Number (%) of people that received day care visits provided by Marie Curie
- Mean (SD), median (IQR) and range of number of day care visits provided by Marie Curie per person

3.5 Hospice based services

Unless otherwise indicated analyses reported overall, then according to months to death. Subsequent analyses to explore health and social care use stratified by sex, age group, SIMD quintile, ethnicity (White vs. BAME) and cause of death (cancer vs. non)

- Total number of hospice in-patient admissions accounted for by cohort
- Crude rate of hospice admission
- Number (%) of people with ≥ 1 hospice admission
- Mean (SD), median (IQR) and range of hospice admissions per person
- Of those with ≥ 1 hospice admission, mean (SD), median (IQR) and range of hospice admissions per person
- Of those with ≥ 1 hospice admission, mean (SD), median (IQR) and range of time (days) from first hospice admission to death
- Of those that died in hospice, mean (SD), median (IQR) and range of time from terminal admission to hospice to death
- Of those that died in hospice, number (%) that had cancer as an underlying cause of death
- Total number of hospice bed days accounted for by cohort
- Mean (SD), median (IQR) and range of number of hospice bed days per person
- Of those with ≥ 1 hospice admission, mean (SD), median (IQR) and range of bed days per person
- Of those with ≥ 1 hospice admission, mean (SD), median (IQR) and range of bed days per admission
- Summary of location 'admitted from' listed in index episode of CIS (N, %)
- Summary of principal diagnosis listed in index/last episode of CIS (N, %)³⁶
- Number (%) of people that attended hospice based day care
- Of those attending hospice based day care, mean (SD), median (IQR) and range of day care sessions attended per person

³⁶ See previous note SMR regarding selection of episode of CIS from which to derive data on reason for admission

- Total number of hospice day care sessions accounted for by cohort
- Number (%) of people that attended hospice-based out-patient clinic
- Of those that attended hospice-based outpatient clinic, mean (SD), median (IQR) and range of out-patient attendances per person
- Total number of hospice outpatient attendances accounted for by cohort
- Number (%) of people seen by specialist palliative care community team
- Of those seen by community specialist palliative care team, mean (SD), median (IQR) and range of contacts per person
- Total number of community specialist palliative care team contacts accounted for by cohort
- Of those seen by community specialist palliative care team, mean (SD), median (IQR) and range of time (days) from first contact with community specialist palliative care team to death

3.6 Social care data

Unless otherwise indicated analyses reported overall, then according to months to death. Subsequent analyses to explore health and social care use stratified by sex, age group, SIMD quintile, ethnicity (White vs. BAME) and cause of death (cancer vs. non)

- Number of people with a social work contact in the last year of life
- Of those with a social work contact, mean (SD), median (IQR) and range of time (days) from first social work contact to death
- Number of people that had ≥ 1 completed care plan
- Of those with a completed care plan, mean (SD), median (IQR) and range of time (days) from first completed care plan to death
- Number of people that had one or more care plan indicating that the client belonged to a palliative care group
- Of those identified as being in a palliative care group, mean (SD), median (IQR) and range of time (days) from care plan indicating person in a palliative care to death
- Number of people that had a care plan indicating that the client had support from an unpaid carer
- Number of people that had a care plan indicating that the client's carer was receiving services
- Number of people residing in nursing home care (not respite care)
- Number of incident admission to nursing home (not for respite)
- Number of people in residential care (not respite care)
- Number of incident admission to residential care (not for respite)
- Number of people in other supported accommodation
- Number of incident admission to supported accommodation
- Number of people living alone in main stream housing
- Number of people receiving home care
- Summary (N, %) type of home care service received
- Total number of home care hours received by the cohort
- Of those receiving home care, mean (SD), median (IQR) and range of hours of home care received per person

- Of those receiving home care, number (%) of people receiving:
 - 2 hours or less, 2 – 4 hours, 4 – 10 hours, >10 hours/week
- Number of people receiving overnight home care
- Total number of overnight care hours received by the cohort
- Of those receiving overnight care, mean (SD), median (IQR) and range of hours of overnight care received per person
- Number of people receiving day care
- Total number of day care sessions received by the cohort
- Of those receiving day care, mean (SD), median (IQR) and range of day care sessions received per person
- Number of people accessing any respite care
- Number receiving respite nights at home
- Total number of respite nights at home received by the cohort
- Of those receiving respite nights at home, mean (SD), median (IQR) and range of hours received per person
- Number receiving respite nights not at home
- Total number of respite nights at not home received by the cohort
- Of those receiving respite nights at not home, mean (SD), median (IQR) and range of hours received per person
- Number receiving respite days at home
- Total number of respite days at home received by the cohort
- Of those receiving respite days at home, mean (SD), median (IQR) and range of hours received per person
- Number receiving respite days not at home
- Total number of respite days not at home received by the cohort
- Of those receiving respite days not at home, mean (SD), median (IQR) and range of hours received per person
- Number of people receiving equipment or adaptations to their home
- Summary of equipment/adaptations (N, %)
- Number of people receiving self-directed payments
- Number of people receiving reablement
- Number of people receiving meals at home
- Number of people accessing any social care service in the last year of life

3.7 Composite end points

- Number (%) of people that used any specialist palliative care service
 - Hospital SPC team, community SPC team, in-patient hospice care, out-patient hospice care, day care
- For those that used any specialist palliative care service, cross tabulation of the type of service received in the last year of life (N, %)
- For those that used any specialist palliative care services, mean (SD), median (IQR) and range of time (days) from first contact to death
- Number (%) of people who used any hospital-based service
 - In-patient, out-patient, day hospital, emergency attendance, GP OOH services, NHS24)

- For those that used any hospital-based service cross tabulation of services used in the last year of life (N, %)
- Number (%) of people who used any social care service
- For those that used any social care service cross tabulation of services used in the last year of life (N, %)
 - Nursing home, residential care, other supported accommodation, home care, respite care, day care, equipment/adaptations, self-directed payments, reablement, meals at home
- Number (%) of people who had any input from community nursing (district nursing or Marie Curie)
- For those that had input from any community nursing, cross tabulation of services used during the last year of life (N, %)
 - District nursing, Marie Curie nursing
- Number (%) of people who had no contact with any health or social care services in the last year of life
- Number (%) of people who used hospital based services only
- Number (%) of people who used social care services only
- Number (%) of people who used community services only
- Number (%) of people who used hospice based services only
- Cross tabulation of service use (N, %)
 - Hospital-based, hospice-based, community-based, social care, none

3.8 Other

- Proportion of time in last 6 months spent at home or in a homely setting

3.9 Comparison with population from Renfrewshire HSCP

- Proportion of all hospitalisations (elective or emergency) in adults living in the Renfrew HSCP area over the study time period (1 January 2015 through 31 December 2016), accounted for by the cohort
- Proportion of all *emergency* hospitalisations in adults (18 years and over) living in the Renfrew HSCP area over the study time period (1 January 2015 through 31 December 2016), accounted for by the cohort
- Proportion of all bed days (elective or emergency admissions) in adults living in the Renfrew HSCP area over the study time period (1 January 2015 through 31 December 2016), accounted for by the cohort
- Proportion of all emergency bed days in adults (18 years and over) living in the Renfrew HSCP area over the study time period (1 January 2015 through 31 December 2016), accounted for by the cohort

TABLES

Table 1. Causes of Death with associated ICD10 codes³⁷

Causes of death	Derived from PHE ICD 10 coding ³⁸
Cancer	C00 – C97
Trachea, lung and bronchus	C33-C34
Breast	C50
Colorectal	C18-C21
Prostate	C61
Respiratory Disease	J06-J18, J20-J22, J45, J46,
Chronic lung disease	J40* – J44*, J47*
Cardiovascular Disease [§]	All I codes except I12, I13, I81 and I85, G45*, Q20* – Q26*
Cerebrovascular disease	I60* – I64*, I66* - I67*, I69*, G45*
Heart failure	I50* - I51*
Liver Disease	K70*, K71, K72*, K73*, K74*, K75*, K76*, K770, K85, K830, K831, K383, K839, B008, B251, B15*, B16*, B17*, B18*, B19*, B581, D868, O226, O904, Q446, T391, T864, Z944, Y830, I81, I85*
Renal Disease	N17*, N18*, N28*, I12*, I13*
Alzheimer's (AD), Dementia, Senility	F01*, F03*, G30*, R54*
Neurodegenerative Disease	G20*, G12.2, G35*, G10*, G90.3 G23.1
External Causes of Death	S00 – Y98
Other	Any other cause of death that does not fall into above categories

*Indicates inclusion of 4th digit ICD codes; § Excludes vascular dementia which is included in AD, Dementia and Senility and diagnoses associated with renal disease.

³⁷ ICD codes derived from PHE disease specific profiles with the exception of site specific cancers which have been removed and added to 'cancer' group. These classifications may identify disease specific groupings with greater sensitivity and specificity than NRS grouping in Table 2.

³⁸ <http://www.endoflifecare-intelligence.org.uk/resources/publications/>

Table 2. Causes of death & associated ICD 10 codes: NRS³⁹

Causes of death	Derived from PHE ICD 10 coding⁴⁰
All causes	A00 - R99, U00 - Y89
Certain infectious and parasitic diseases	A00 - B99
Neoplasms	C00 - D48
Malignant neoplasm	C00 – C97
Disease of the blood and blood forming organs and certain disorders involving the immune mechanism	D50 - D89
Endocrine, nutritional and metabolic disease	E00 – E90
Diabetes Mellitus	E10 – E14
Mental and behavioural disorders	F00 - F99
Diseases of the nervous system and sense organs	G00 – H95
Diseases of the circulatory system	I00 - I99
Ischemia heart disease	I20 – I25
Other heart disease	I30 – I33, I39 – I52
Cerebrovascular disease	I60 – I69
Diseases of the respiratory system	J00 - J99
Chronic lower respiratory disease	J40 – J47
Diseases of the digestive system	K00 – K93
Chronic liver disease	K70, K73 – K74
Diseases of the genitourinary system	N00 – N99
Pregnancy, childbirth and the puerperium	O00 – O99

³⁹ <https://www.nrscotland.gov.uk/statistics-and-data/statistics/statistics-by-theme/vital-events/general-publications/vital-events-reference-tables/2015/section-6-deaths-causes>. Note to avoid disclosure it may be necessary to collapse some categories of cause of death when reporting data.

⁴⁰ <http://www.endoflifecare-intelligence.org.uk/resources/publications/>

Congenital malformations, deformations and chromosomal abnormalities	Q00 – Q99
Symptoms, signs and abnormal clinical and laboratory findings not elsewhere classified	R00 – R99
External causes of morbidity and mortality	V01 – Y89 (incl U50.9)

*Note give the study will examine adults only causes of death relating to the perinatal period have been removed

Table 3. Causes of death deemed to be unexpected with associated ICD 10 codes¹

Acute myocardial infarction	I21*, I22*
Pulmonary embolism	I26*
Pulmonary aneurysm	I281
Sudden cardiac death	I461
Cerebrovascular disease	I60-I69
Aortic aneurysm	I71*
Acute respiratory disease, including influenza and pneumonia	J10-J29, J85-J86, J91-J96
Injury, poisoning, other consequences of external causes	S00-T98
External causes	V01-Y98

*Indicates to 4th digit

Table 4. Causes of death & associated ICD10 codes: the Murtagh approach⁴¹

Malignant neoplasm:	C00 – C97
Heart disease incl cerebrovasc disease:	I00-I52, I60 – I69
Renal Disease:	N17, N18, N28, I12, I13
Liver Disease:	K70 – K77
Respiratory Disease:	J06-J18, J20-J22, J40-J47, J96
Neurodegenerative disease:	G10, G20, G35, G122, G903, G231
Alzheimer’s, dementia & senility:	F01, F03, G30, R54
HIV/AIDS:	B20-B24

Table 5. Distribution of external causes of death & associated ICD 10 codes⁴²

Injuries	S00 – T19
Burns and frost bite	T20 – T35
Poisoning, toxicants & other unspecified	T36 – T78
Transport accidents	V01 – V99
Fall & other accidental injury	W00 – X59
Intentional self-harm	X60 – X84; Y10 – Y34
Assault	X85 – Y09; U50.9
Complications of care & other	T79-T98, Y35–Y36; Y40–Y98

⁴¹ Murtagh *et al.* How Many People Need Palliative Care? A study developing and comparing methods for population-based estimates. *Pall Med.* 2014;28(1):49-58.

<http://journals.sagepub.com/doi/10.1177/0269216313489367>

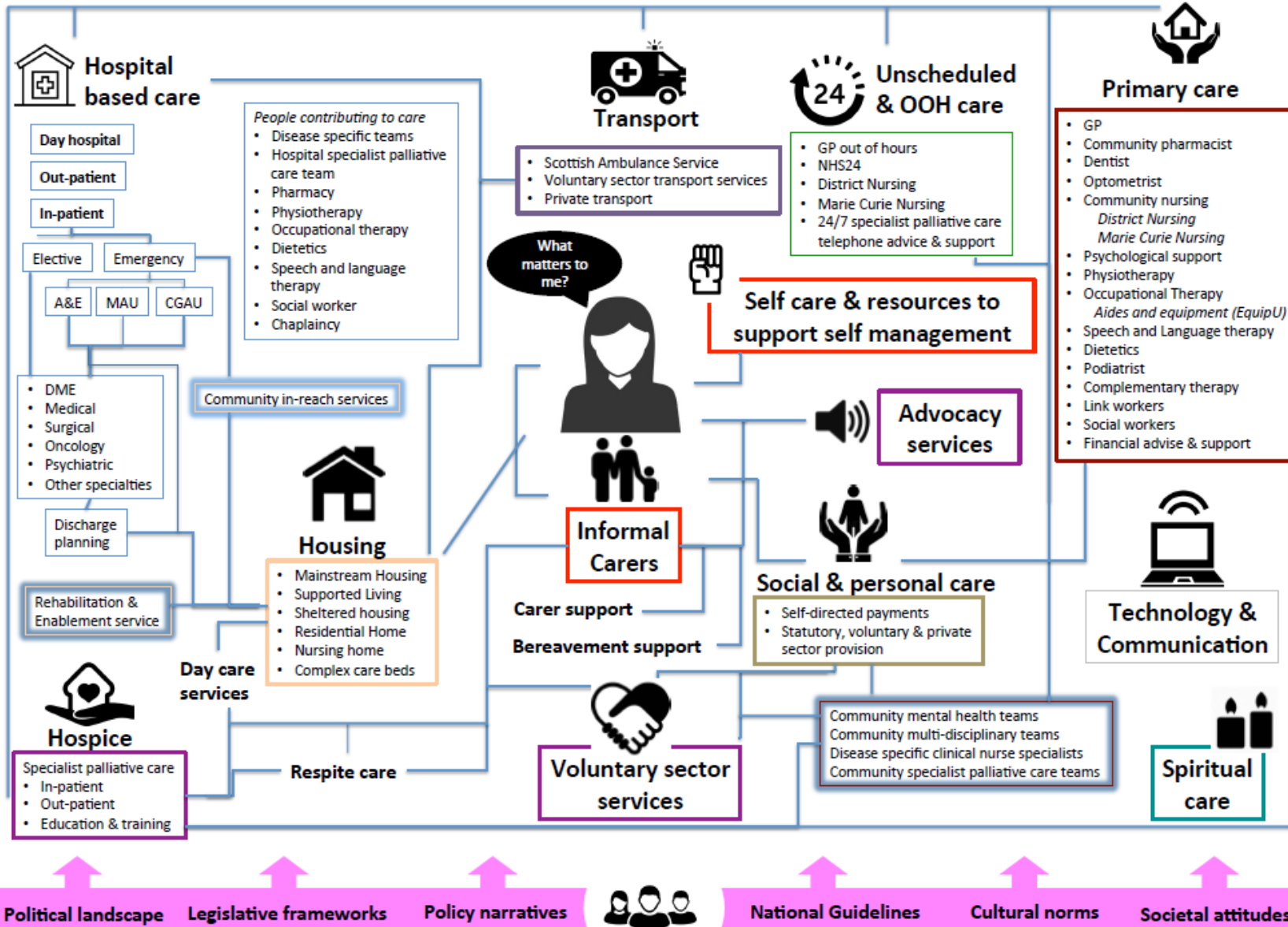
⁴² http://www.endoflifecare-intelligence.org.uk/resources/publications/external_causes_of_death

Table 6: ICD10 codes for LTCs (ISD/SOURCE Methodology)

LTC	ICD10 Code
ARTHRITIS	M05 - M19, M45- M47
ASTHMA	J45.0, J45.1, J45.9, J46X
ATRIAL FIBRILLATION	I48X
CANCER	C00-C97 (Not all 4 digit CD10 codes applicable)
CEREBROVASCULAR DISEASE	I60-I69 (Not all 4 digit CD10 codes applicable)
CHRONIC LIVER DISEASE	K70 – K76 (Not all 4 digit CD10 codes applicable)
CONGENITAL PROBLEMS	Q00 – Q07, Q10 – Q18, Q20 – Q28, Q30 –Q34, Q38 – Q45, Q50-Q55, Q60 –Q93, Q95 – Q99. (Not all 4 digit CD10 codes applicable)
COPD	J41 – J44 (Not all 4 digit CD10 codes applicable) & J47X
DEMENTIA	G30, F00 – F03 & F05 (Not all 4 digit CD10 codes applicable)
DIABTETES	E10-E14
DISEASES OF THE BLOOD & BLOOD FORMING ORGANS	D50 – D53, D55-D77, D80 – D84, D86 & D89 (Not all 4 digit CD10 codes applicable)
EPILEPSY	G40 – G41 (Not all 4 digit CD10 codes for G41 applicable)
HEART DISEASE	I20 –I25 (Not all 4 digit CD10 codes applicable)
HEART FAILURE	I50.0, I50.1 and I50.9
MS	G35X
OTHER DISEASES OF DIGESTIVE SYSTEM	K00 – K14, K20X, K21 – K23, K25-K29, K30X, K31, K35-K38, K40-K46, K50-K52, K55 – K63, K65 – K67, K70 – K77, K80 – K83, K85X, K86 – K87, K90 – K93. (Not all 4 digit CD10 codes applicable)
OTHER ENDOCRINE METABOLIC DISEASES	E00-E07, E15X, E16, E20-E32, E34-E35, E70-E80, E83-E85, E86X, E87-E89, E90X (Not all 4 digit CD10 codes applicable)
PARKINSONS DISEASE	G20X, G21, G22X (Not all 4 digit CD10 codes for G41 are applicable)
RENAL FAILURE	N03, N18, N19X, I12,I13 (Not all 4 digit CD10 codes applicable)

Appendix 1: Whole system map of palliative and end of life care provision in Renfrew HSCP

A high level whole system map for palliative and end of life care in Renfrewshire HSCP





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