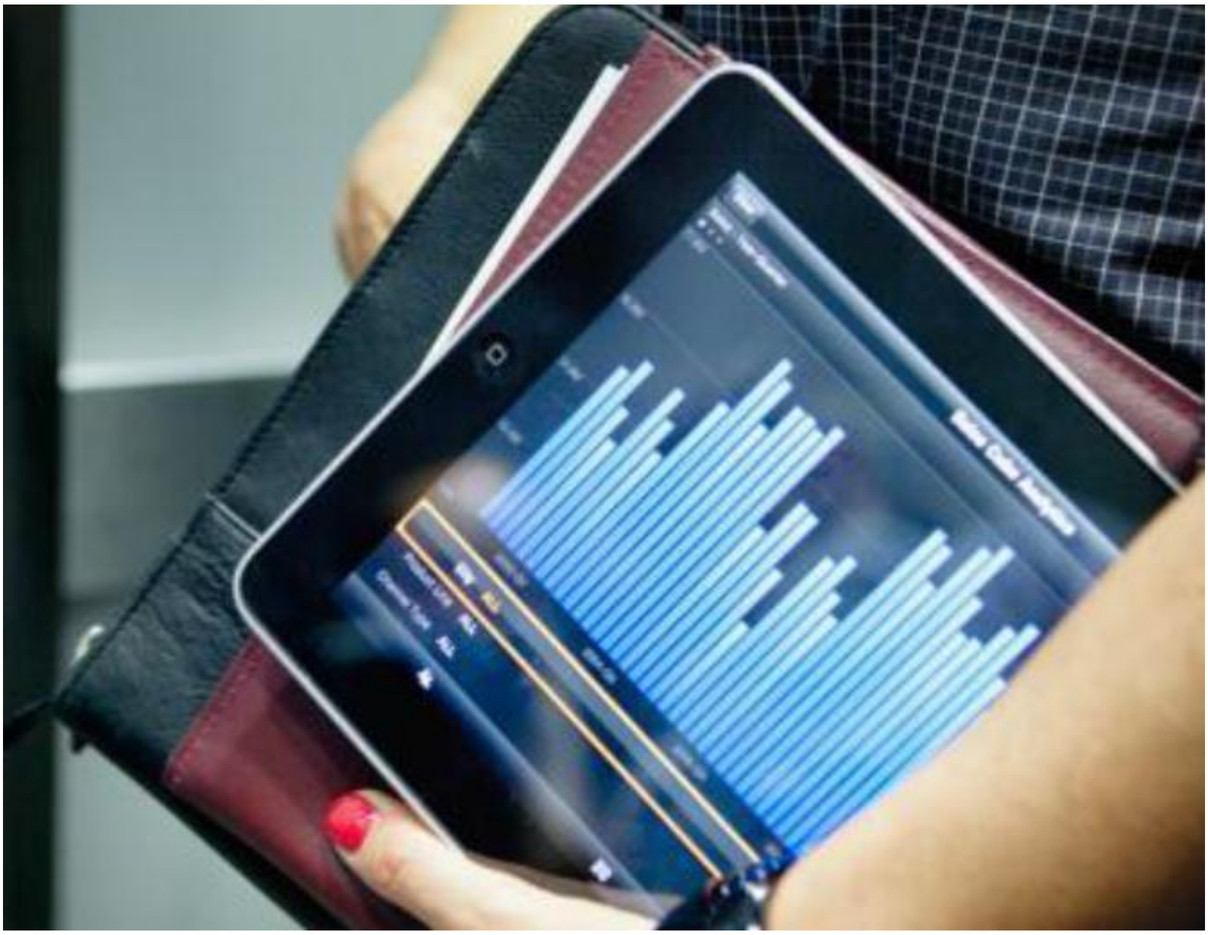
Public Data for the Private Sector



Better solutions for an ageing population

November 2015

Foreword

By Dame Karen Dunnell

The Longevity Science Panel independently monitors scientific evidence that could potentially explain changes and differences in life expectancy in the UK. It aims to cover changing epidemiological, biological and socio-demographic factors as well as the impact of developments in health care. Its conclusions will be openly disseminated, with the intention of promoting public interest in the factors that influence life expectancy.

The Panel has produced three previous reports, which have looked at the impact that socio-economic factors and gender differences have on lifespan, at an individual, as well as at a population level, with the third report focusing on the biology of ageing. This fourth report looks at the subject of the private sector's access to public sector databases about individuals in our society.

Insurance companies and actuaries have always had access to anonymised information from birth and death registers – the oldest example of person-based administrative data from government. Increasingly of interest are comparable data sets from the National Health Service and other public services which could throw light on health status, care and other needs. Anonymised individual records allow users to build models and carry out analyses that provide more accurate estimates for different population groups in our society.

Such access has become more difficult in recent years. The report looks at the recent history and summarises the complex legislation surrounding data access, discusses the potential benefits from improved access to Government databases by the private sector and makes a series of recommendations for the future.

Our founder chairman, Sir Derek Wanless, was a committed user of statistical databases. I am sure he would have supported our conclusions and recommendations and welcomed this report in the series of position papers which he established.

Contents

Acknowledgements

This publication was prepared by:

Dame Karen Dunnell, Chair

Professor Sir Colin Blakemore

Professor Steven Haberman

Professor Klim McPherson

Professor Sir John Pattison

Other Contributors:

Joseph Lu, Secretariat to Longevity Science Panel, Legal & General

Madhavi Bajekal, University College London

Hande Love, Legal & General

Alison Martin, Crystallise

Chris Martin, Crystallise

Wun Wong, Legal & General

Longevity Science Panel Membership

Dame Karen Dunnell (DCB), Chair of the Longevity Science Panel and formerly National Statistician and Chief Executive of the Office for National Statistics, with experience and understanding of data resources, socio-demographic changes and public policy, is well placed to assess the potential benefits from access to national data by the private sector and the problems that exist in obtaining such access.

Professor Sir Colin Blakemore, Professor of Neuroscience & Philosophy at the University of London, Emeritus Professor at Oxford and former Chief Executive of the Medical Research Council, brings knowledge of the data requirements for medical research.

Professor Steven Haberman, Professor of Actuarial Science and Dean of Cass Business School, is experienced in statistical modelling and mortality research, and has the expertise to consider how to convert research findings into a format for actuarial analysis.

Professor Klim McPherson, a retired public health academic at University of Oxford and Chair of UK Health Forum, is recognised for his work on obesity and the wide ranging detrimental effect this has on the health of the population and particular sub-groups.

Professor Sir John Pattison, formerly Director of Research and Development at the Department of Health in England, is well placed to assess the health services' ability to deliver the changes emerging from health research findings.

Funder: Legal & General.

Executive Summary

By 2035, it is estimated that the proportion of the UK population aged 65 or older will increase by almost 50%, yet many adults will have inadequate savings and pensions for a lengthy retirement. The increased strain on the providers of services such as pensions and annuities, retirement housing, and health and social care cannot be met adequately by a constrained public sector, as was acknowledged in the House of Lords Select Committee report *Ready for Ageing?,* published in 2013.

The report called on the private and public sectors to work together to resolve the challenges posed by the ageing population. For their services to be sustainable, providers need to predict the future needs of the population accurately and meet these needs in an economically viable manner. This informed service planning requires access to robust data at a level granular enough to allow reliable predictions for the needs of an individual.

A succession of legislation has attempted to secure the public good that can arise from sharing of appropriate data within the public and private sectors while maintaining the fundamental right of an individual to have their confidentiality protected by those holding their data. However, the different contexts and purposes of each piece of legislation has led to confusion, ambiguity, and contradictory messages about what data may be shared, and in which context. The result has been an inconsistent barrier to access to necessary data, in particular affecting the private sector, with a negative impact on service provision.

In this paper, the Longevity Science Panel explores potential opportunities and barriers to the provision of publicly-held data that are needed if the private and public sectors are to collaborate effectively and make appropriate decisions to meet the full needs of the ageing population in the UK.

The range of such data is vast, so the paper focuses on nationally-collected statistics and other anonymised population data, as this is an area where there is most confusion about appropriate access. The issues and challenges caused by this lack of clarity are explored by focusing on three key areas of relevance to an ageing population that were highlighted in the House of Lords report: pensions, housing, and health and social care.

There is considerable overlap in the data needed to inform the provision of adequate services for the ageing population. Essentially, providing retirement income such as annuities and appropriate specialist housing, and predicting health and social care needs, all depend on an accurate assessment of the likely lifespan of an individual as well as disease progression trajectories that describe the need for additional support over time.

Although aggregated data may be available, the most accurate modelling of mortality and morbidity progression requires a degree of granularity to the anonymised individual level that may not be available to the private sector. It is the granularity of the data and not the identifiability of the data that is needed. In particular, anonymised individual-level data, to reflect the range of socio-economic classes, combinations of risk factors and comorbidities, would allow more reliable estimation of how long any individual could be expected to need specialist housing, or will need to draw an enhanced annuity, or what his or her social care needs are likely to be.

The pensions industry helps the public manage longevity risk though financial products such as annuities, but generic pricing of these have rendered them unattractive to many. Recent freedoms around the use of pension savings have raised concerns that a growing proportion of the elderly will run out of income to support their increasingly long retirements.

There is a need for new, competitively priced retirement income products, but their viability depends on assumptions about how long policyholders can expect to live. The availability of health data of anonymised individuals could help, but determining how longevity is associated with complex health-related factors, including the interaction between age, risk factors and existing diseases, requires individualised rather than aggregate anonymised data. Confusion about what information is legally permitted may lead to restrictions in access to such data by the private sector.

The finance industry has been urged to provide solutions to help older home owners access the money locked up in their properties. Appropriate pricing of equity release products, such as lifetime mortgages, also requires data on how mortality, disability and morbidity change with time for elderly homeowners, and how this affects the need for and timing of residential care. However, such data are often not collected.

The housing market is delivering much less specialist housing for older people than is needed. Planning for better provision of retirement accommodation requires data on needs and preferences of elderly adults to determine the rate of decrease of independence and need for greater support across subgroups, the costs and appropriate pricing of specialist housing, and how its provision might reduce health and social care costs. This is too often either not available to the public sector at a sufficiently granular level, or is not collected.

Adequate provision of health and social care for the elderly population requires forward planning, based on analysis of data on typical disease trajectories, progression of frailty and the level of required care needed at each stage, with its associated costs. The complex multiple morbidity experienced by the elderly means that access again is needed to individual anonymised data to see how disease and risk factors interact to determine the need for support.

To improve the provision of publicly-held information for decision-making by both the public and private sectors, we put forward four recommendations.

1. We recommend the formation of a coherent and publicly acceptable legal structure and entity to govern the collection, management and dissemination of public statistics, data and information to support the public good.

- We welcome the Law Commission's recommendation that *"a full law reform project should be carried out in order to create a principled and clear legal structure for data sharing, which will meet the needs of society"*.
- We propose that the reform should include the provision of statistics, information and data for private sector industries that carry out commercial or non-commercial activities for the public good, rather

than exclusively focusing on public services.

2. We recommend that the 'public good' be defined in a way that includes any activity that benefits society or the economy, particularly where that activity is aligned with public policy.

- The lack of a clear definition of the term 'public good' in relation to existing legislation, and uncertainty in its interpretation, is impeding access to information, statistics and data. This could lead to missed opportunities to develop improved services or products for the public.

3. We recommend that strategies are employed to improve the appropriate access of both the public and private sectors to all publicly-funded data, information and statistics, while protecting the privacy of individuals and the public interest. These might include:

- principle-based definitions of the levels of granularity of anonymous data that do not require any restriction on access;
- licensed third-party data warehouses that can analyse sensitive data for other organisations;
- software that enables aggregate analysis of sensitive data without allowing access at the individual level; and
- the UK Statistics Authority extending the remit of its Administrative Data Research Network to the private sector.

4. We recommend that private sector and public bodies are included in discussions to specify what public data and information are needed for the benefit of society and the economy.

- The private sector should be actively encouraged to join Statistics User Forum groups that are organised by the Royal Statistical Society.
- The private sector should be encouraged to participate in consultations and reviews about the collection and use of statistical databases.

Section 1. Introduction

The Longevity Science Panel (LSP) has been monitoring trends, generating discussion and forming views on issues relating to the longevity trend within the UK. The opinion of the panel has been shared with the public through media engagement and publication. Our work aims to be a source for learning and understanding on the implications of scientific developments on life expectancy within the UK.

All of our work depends on the availability of information about ageing in the population and the factors that influence it. Whilst the public sector provides for health and primary/secondary educational needs in full it does not aim to provide pensions, social care or housing beyond basic requirements or for particular groups of people. These are policy areas where there has been much development and discussion in recent years. Hence LSP began to widen its remit for potential research to include the provision of these services for our ageing population. This mirrors the development in Legal and General of products for the elderly.

At around the same time, in 2014, there was a crisis in the development of an information source about patients in General Practice, known as care.data, which we discuss in more detail in section 4.3 of this report. This data source would have been of great interest to LSP, as it provides complementary information about age and causes of death, hospital inpatient spells, as well as epidemiological data on multiple morbidity, age of onset of disease, disability and dependency.

The communication about care.data to the public raised many questions about the confidentiality of the data and who and how users would have access[1]. An ensuing investigation into other data releases by the NHS revealed that Hospital Episode Statistics (HES) data had been sold to the insurance industry, the implication being that insurers would use it to identify individual policy holders or prospective customers. Not surprisingly all data releases from the NHS were halted, even to those researchers whose work had already cleared the relevant administrative and ethical hurdles.

It has always been more difficult for the private sector to access some government databases compared with the access granted to academic researchers. This now became an urgent issue for LSP, so we made it the topic of this, our fourth report.

We have made the case that **information collected from the public in the course of its use of public sector services must be available, with the right safeguards, to all who need to plan and provide services to develop our society and economy**. This must include the private sector with similar responsibilities in areas not covered by the State, which public policy expects to fill the gaps.

This paper examines the opportunities and barriers to the provision of publicly-held data that address the growing needs of an ageing UK population. As such, this paper is focusing solely on data available for the UK. Additional insights might be learned from a comparison with other countries. However, to gain useful knowledge from this comparison would require an analysis of the relevant legislation and social attitudes in each country, and information about how these have been interpreted regarding private sector access to the data. Such detailed international

---

[1] Carter et al. (2015)

assessment is beyond the scope of this paper.

1.1 Issues to do with the ageing population

The continual rise in life expectancy, combined with the fall in fertility, has led to a rapidly ageing population. From 2015 to 2035, the number of people aged 65 and older in the UK is expected to rise from 11.6 to 17.3 million, an increase of 49%.[2] For the same period, this corresponds to a rise from 18% to 24% in the proportion of people aged 65 and above. This means that the aged dependency ratio, the number of working age people to each person over the age of 65, will fall from 3.2 to 2.8. These demographic changes produce both unprecedented challenges and opportunities for society.

In the conclusion to his 2002 report for HM Treasury our founding Chair, Sir Derek Wanless, highlighted the financial implications of a deteriorating dependency ratio.[3] If life expectancy continues to rise with no proportionate improvement in healthspan, there will be increasing pressure on areas of public spending, including pensions. In the context of a rising retirement age, projections of public health are an important part of evaluating the adequacy of pension provision.

The second Pensions Commission Report of 2005 noted that the current system of private funded pensions, combined with the state system, will deliver increasingly inadequate and unequal results, in part as a consequence of this falling dependency ratio.[4] **These problems cannot be solved through changes to the state system alone.**

The Commission also postulated that worsening trends in lifestyle such as increasing obesity among young adults and children may lead to a fall in life expectancy in the long-term. However, over the next 30 years, these changes might have a greater negative impact on the health of the working-age population than on elderly pensioners, further compounding the problems of a deteriorating aged dependency ratio.

Better epidemiological modelling depends on developing access to better data sources such as the English Longitudinal Study of Ageing and the Household Assets Survey. Evolving public health issues that may affect future mortality rates need to be properly understood, if adequate pensions are to be provided that minimise the risk and cost. Detailed simulation modelling such as that developed by the UK Health Forum for the Foresight Report on obesity contributes to the evaluation of longevity risk, but demands a high granularity of the data required for parameterising such models.[5]

In their 2013 report *Ready for Ageing?* the House of Lords Select Committee on Public Service and Demographic Change highlighted the issues confronting the UK's ageing population. They include:

- **Savings and pensions**. *"Many people are not saving enough, and the Government must work to improve defined contribution pensions, which are seriously inadequate for many. People need reliable, data-driven, help to make better use of the wealth tied up in*

---

[2] Office for National Statistics. National population projections 2012.
[3] Wanless (2002).
[4] Turner (2005).
[5] Butland (2007).

their property to support their longer lives".
- **Housing**. *"The housing market is delivering much less specialist housing for older people than is needed. Central and local government, housing associations and house builders need urgently to plan how to ensure that the housing needs of the older population are better addressed".*
- **Health and Social care**. *"Radical changes to the way that health and social care is delivered are needed to provide appropriate care and to address future demand. The quality of healthcare for older people is not good enough now; social care and its funding are already in crisis".*

As the NHS provides the vast majority of healthcare-related services within the UK, we focus instead on the shortfall in the provision of adequate retirement income, housing stock and social care services; areas where we feel the contribution of public-private partnerships can provide the greatest benefit. Nevertheless, as the need for specialist housing and social care depends ultimately on the health and disability of the individual, we feel the provision and examination of health data itself is necessary to support the services addressed in this paper. We will elaborate on this and other issues in later sections.

1.2 The need for data to facilitate greater private provision

For an ageing population, increased support and service delivery costs necessitate a greater collaboration across major sectors of care and housing provision, including government, public-private partnerships, and charitable and voluntary organisations. A constrained public sector cannot deliver all that is necessary, thereby requiring a deeper commitment and closer working relationship between the sectors.

Gaps in the availability of robust and comprehensive data will hinder the provision of suitable pension products, housing and health and social care services. To help address the shortfall, we will argue that access to more granular forms of data will aid in the determination of the timing and service needs of the ageing population. For instance, we submit that access to anonymised health, social care or housing data can provide a more complete and joined-up picture of disease progression and the need for additional support, thereby informing the planning and provision of services to meet current and future need.

Much of this data is collated and held within the public sector, as either survey or administrative data. We differentiate between the two data types accordingly:

- **Survey data**: data derived from a sample of a given population. The data are often analysed statistically and used to characterise the sampled population.
- **Administrative data**: includes routinely collected public sector data obtained from governmental departments, agencies, local authorities, birth and death registries and general practice records. These data are often collected on a longitudinal, or continuous, basis.

Survey data are valuable because they allow the user to carry out his or her own analysis and use all the data items available in the data set. Identification of individuals is made even more unlikely because only samples of the population are included. Data from administrative systems can be even more useful because they cover whole populations and tend to be collected on a continuous basis.

1.3 Data protection issues

Nationally collected personal data are anonymised according to strict protocols. At the heart of legislation is the protection of personal data, defined by the Data Protection Act (1998) as data that relate to a living individual who can be identified from those data, or from those data and other information that are, or could become, in the possession of an organisation.[6] Examples of personal data include the individual's full name, date of birth, gender and address.

Changes in technology have expanded the range and volume of data that are being recorded by public bodies. The Government Statistical Service (GSS), government departments and agencies, regional and local government produce large and increasing amounts of data. However, the expansion of the amount of data recorded has led to issues about necessary barriers for such data to be shared between public bodies and with the private sector. These issues have been investigated in relative detail by The Law Commission (2014). They conclude that public bodies cannot always share the necessary data, which has resulted in missed opportunities to provide better services.

As many forms of data are collected, we feel it is important to clarify what we are concerned with in this paper. We hold the view that only anonymised data should be made available to the private sector, in compliance with legislation to promote public trust. Anonymisation is the process that aims to make it impossible for a third party to identify an individual from his or her data.

We are therefore not interested in access to identifiable data. **Our main concern is about barriers to access by the private sector of anonymous, individual-level data at a granularity that allows complex analyses that can take into account the influence of co-factors on predicting outcomes – especially when these barriers do not apply to public sector organisations.**

Both survey and administrative data can only be used by researchers when they have been subjected to anonymisation or sampling processes. These processes have largely been 'conquered' to allow access to population census data. The UK Statistics Authority has begun work on such a service to parallel the work by the Economic and Social Research Council (ESRC) which makes survey data sets available. Although only available to academics at present, we believe it should be accessible for private sector use and that similar systematic services should be established for other relevant data.

Some examples of relevant data that could be used to support service planning and provision for an ageing population include death rates associated with individual risk factors such as smoking, or rates of entry into care home of people diagnosed with a stroke. Appropriately anonymised data would contain information such as age, gender, smoking status, blood pressure levels, socio-economic circumstances and disability measures of individuals[7].

---

[6] Data Protection Act 1998 (c29). Part 1, p.2.

[7] De-identified data is used to describe personal data that have been processed to remove personal identifiers such as name and postcode.

1.4 Data anonymisation

A report from the Law Commission has described some of the approaches and limitations to the anonymisation of personal data.[8] Rapid advances in technology and the increased deployment of ‘Big Data’ analytics to a growing variety of data and metadata have made the risk for re-identification much greater.

This paper recognises that personal data sets that have been altered through an anonymisation process “*may or may not be successfully rendered anonymous, depending on the success of the techniques employed*”.[9] We submit therefore that **a trade-off be struck and a balance maintained between absolute privacy and the ability to use such data**. The determination and provision of such trade-offs should be made known to the public, with education of the general community made a priority.

To address such issues, the Information Commissioner’s Office (ICO) has published a code of practice on the anonymisation of data, including topics such as pseudonymisation, aggregation, banding and organisational safeguards.[10] The ICO acknowledges the anonymisation of personal data cannot, with absolute certainty, eliminate the risk of re-identification. Rather, the processes for anonymisation represent a sliding scale of risk for the re-identification of personal data.

With this in mind the UK Anonymisation Network, in consultation with the Law Commission, has recommended the aim of data anonymisation should instead be to “*produce data which are anonymous enough in proportion to their sensitivity*”.[11] The classification, use and safety of the data should therefore be considered within this context.

1.5 A way forward

Adapting current pension and savings products, or developing new services, provides an opportunity to reduce the risk of financial hardship at older ages.

In this paper, we focus on case studies regarding pensions, housing and social care provision. **We aim to show how greater access to appropriate data might be used in scientific research and mathematical modelling to help to plan and provide better services for the ageing population.**

By improving access to such data, at an appropriate level of detail, the private sector would be better able to:

- **understand** the uncertainty associated with future risk of multiple chronic disease, disability, and frailty and their cumulative impact on longevity, to provide products such as enhanced annuities;
- **innovate** or fine-tune existing products and/or provide cover in new or hitherto neglected areas, such as social care insurance;
- **promote financial security** for older age groups by designing products to help people decide how to manage their assets, for example savings and housing wealth;
- **extend coverage** beyond the current concentration in higher income and socio-economic groups to widen the scope of affordable policies on offer; and

---

[8] Law Commission (2014).
[9] Ibid., No. 6.11. p.94.
[10] Information Commissioner’s Office (2012).
[11] Law Commission (2014), p.54.

Consultation meeting no.42 – UK Anonymisation Network.

- **respond flexibly** to people’s specific needs/circumstances and benefit the consumer by providing more **accurate pricing**, such as the mathematical modelling of average future health outcomes for groups of similar people.

Section 2. Data to tackle challenges of an ageing population

The actuarial profession has long led the way in collating and analysing data to support services and products for the population. With the evolution of IT systems, there has been an explosion in the range and volume of data that can be recorded and accessed, and the complexity of analyses that can be run to turn data into knowledge.

The growing complexity of technology has occurred in line with increasing challenges from multiple morbidity in the ageing population. It has been estimated that about 70% of people aged 75-79 years have two or more medical conditions.[12] Planning services to support elderly people with complex needs requires access to detailed data that can facilitate modelling of interactions between diseases, interventions and social factors.

In this paper, we will focus on data collected nationally and funded by the UK government that could be of use to the private sector, especially the finance industry. However, we recognise that the private sector and research organisations also contribute highly valuable data that are needed for fully-informed product development and pricing.

Types of data available for an ageing population are as follows:

- **public data**, generally collected by the Office for National Statistics (ONS);
- **health data**, collected from National Health Service hospitals, General Practitioners, or other healthcare providers; and
- **private or personal data**, generally collected via surveys, which may include personal preferences.

Data held by public bodies may be publicly available, such as ONS census data, death registers, and surveys.[13] Other data may be accessible in aggregated form, but more value can be derived from anonymous, individualised data. This is held by the relevant bodies, which have discretion as to whom they allow access.

2.1 Savings and pensions

The *Ready for Ageing?* report stated that *"The Committee urges the Government, pensions industry and employers to tackle the lack of certainty in defined contribution pensions and address their serious defects to make it clearer what people can expect to get from their pension as a result of the savings they make".*

The UK pension system is an example where public policies have been designed to encourage both the public and private sectors to work closely to ensure sufficient provision for retirees. This is demonstrated in a series of law reforms related to pension provision over the last century, including the following:

- Old Age Pensions Act, 1908;
- National Insurance Act, 1946;
- National Assistance Act, 1948;
- Social Security Contributions and Benefits Act, 1992;
- Superannuation and other Funds (Validation) Act, 1992;
- Pension Schemes Act, 1993; and
- Pensions Acts of 1995, 2004, 2007 and 2008.

The result of these policies is a multi-tiered pensions system that is publicly and privately funded, emphasising the importance of interaction between public and private sectors in solving retirement issues. The State provides a basic level of

---

[12] Barnett et al. (2012).

[13] http://www.ons.gov.uk

pension to allow for a minimum level of retirement income. It also provides further pension income that is more closely related to employee's earnings levels. However, there is increasing pressure on employers and employees to take out additional private pensions to boost retirement income, as part of a regulated system. In this paper we will focus on private pension provision in the UK, as it illustrates the alignment of private activities with public policies to serve the needs of the population.

Private pension provision can be made through employer-sponsored pension schemes or individual arrangements. Employer-sponsored pension schemes can exist in the forms of occupational pension schemes, group personal pensions, master trusts and other multi-employer schemes. Individual arrangements include personal pensions, stakeholder pensions and retirement annuities. Various policies have been in place to encourage private pension provision, with examples including the following:

- **Legislation** on the regulation and governance of private pensions to ensure that pension schemes are run in a sound and sustainable manner.
- **Tax exemptions** on contributions and pension fund accumulation to encourage savings.
- Participation of employees is encouraged through the staged introduction of **automatic enrolment** into private pensions or National Employment Savings Trusts in the Pensions Act, 2008, which is expected to complete in 2018.

The majority of private pension arrangements are sponsored by employers and individuals can have their own private pension arrangement by buying personal pensions. Employer-sponsored private pensions can be Defined Benefit (DB), Defined Contribution (DC) or hybrid schemes with features of both DB and DC schemes. With DB pension schemes increasingly closed to new joiners, DC schemes will eventually play a greater role in pension provision in the future.

An individual in a DB pension scheme would be looking to receive a pension that is predetermined by a formula based on the individual's earnings history, tenure of service and age. So, the retirement benefit of a DB scheme member is defined in advance.

In contrast, an individual in a DC pension scheme would have a predetermined formula for the employer's and employee's contribution to the fund. But the retirement benefit is not known in advance and is dependent on the accumulated amount of investment in the fund when the person retires. Consequently, unlike DB scheme members, the provision in retirement of an individual in a DC pension scheme is subjected to various risks, including the following:

- **Savings risk** is the risk of having insufficient accumulated savings in the retirement assets.
- **Market risk** is the risk that throughout the savings and retirement periods the investment returns on retirement assets will have been poor.
- **Inflation risk** is the risk that the rising cost of living will erode the buying power of retirement assets.
- **Interest rate risk** is the risk that at the time of retirement, when converting any accumulated retirement assets to income, the current levels of interest will adversely affect the amount of income to be received.

- **Longevity risk** is the risk that the individual will outlive the total income that can be received from their retirement assets.
- **Health and care risk** is the risk that poor health will result in care bills, which will diminish any accumulated retirement assets.

Most of these risks faced by an individual in retirement could be addressed through the insurance concept of spreading the potential financial loss among a large number of people. For example, an inflation-linked annuity is an insurance product that can help an individual mitigate most risks including inflation, market, interest rate and longevity risks.

Before April 2015, UK pension rules required most people who retired with DC pension savings to purchase an annuity. As a result, many pensioners today have an annuity from DC pension schemes. Since April 2015, the rules have changed, DC pension members no longer have to buy an annuity, and, from 2017, existing annuity holders are expected to be permitted to sell their annuity for cash. Given the increased freedom and choice on how to use DC savings, the Government has set up the agency Pension Wise to provide free and impartial guidance to the public.

Despite greater pensions flexibility leading to a fall in purchase of annuity products in 2015, there are still many annuities bought in the market, including the following:

- lifetime standard annuities;
- fixed-term annuities which provide an income for a set period; and
- enhanced or impaired-life annuities that pay out a higher annuity rate to people who may have a lower life expectancy due to illness or risk factors.

Whether an individual is buying or selling an annuity, its monetary value has to be determined. The value of an annuity depends on market and commercial factors as well as longevity assumptions.

Longevity assumptions are also important for the UK's private DB pension schemes, valued at £2 trillion. Trustees and sponsors of DB pension schemes have been transferring longevity risks to insurance and reinsurance companies through various financial products including bulk annuities and longevity hedges. For example, £35 billion of DB pension liabilities have been hedged in 2014 alone. An emerging feature of this market is the use of medical underwriting to insure all pensioners or subset of pensioners with the highest possible pensions. Medical underwriting uses risk factor and disease information to estimate longevity of retirees, requiring more complex analyses and modelling.[14]

Going forward, the need for a better understanding of longevity at older ages will become more important. According to a large mortality investigation of DB scheme members, about half of male pensioners and 80% female dependants were above the age of 70.[15] For DC pension schemes, retirees now have greater flexibility in terms of when they can buy an annuity, which means that many annuity purchases, or sales through the new secondary annuities market, may be made by older individuals than was previously the case. As the very old are often excluded from clinical trial participation, there is a dearth of robust data on how their longevity may be affected by risk factors and diseases. **Appropriate pricing of annuities and other retirement income products is therefore challenging, but could be made more accurate by better access**

---

[14] Towers Watson. De-risking report 2015.
[15] CMI Working Paper 65 (2013)

to granular health and social care data by providers.

Data requirements for longevity modelling

The longevity of individuals depends on many factors, including the following:

- age;
- socio-economic circumstances;
- risk factors such as smoking, obesity and high blood pressure;
- presence of diseases such as heart disease, diabetes, cancer, stroke, respiratory and other diseases;
- future trends in mortality rates for the population;
- future trends in mortality rates for specific and well-identified groups of individuals within the population; and
- future trends in risk factors, health care delivery, medical advancement and other determinants of health.

A key source of relevant UK data is the Clinical Practice Research Datalink (CPRD)[16], funded by the NHS National Institute for Health Research (NIHR) and the Medicines and Healthcare products Regulatory Agency (MHRA) and managed by the Health and Social Care Information Centre (HSCIC). This is a research service that aims to enable the linkage of NHS anonymised health data with other types of data, and includes the following:

- demographics - age and gender;
- medical symptoms and diagnoses;
- intervention - medicines, vaccines, devices;
- treatment outcomes;
- events leading to withdrawal of a drug or treatment;
- hospital or specialist referrals;
- laboratory test results;
- risk factors - smoking and alcohol consumption;
- socio-economic circumstances; and
- deaths.

Anonymised individual data from CPRD would be useful to help understand how risk factors, combination of diseases, treatments and socio-economic factors are linked to longevity.

A potential result of such scientific research would be a mathematical model to assess mortality risk. Additionally, anonymised individual data from CPRD could be used to test or validate existing mathematical models used to estimate the longevity of annuitants.

There are negative consequences of uncertainty in estimating the life expectancy of individuals in a pension scheme.

- Under-estimating life expectancy can result in a failure to provide an adequate income throughout retirement, resulting in poverty in the elderly when their pension savings are used up, or insolvency in a pension fund or product provider.
- Over-estimating average life expectancy can result in unnecessarily high premiums, making pension provision more expensive than it needs to be.
- Where uncertainty is high, risk may be aggregated across all individuals. This can result in those who are relatively sick with lower life-expectancies unfairly subsidising the longer retirement of those who are relatively well with longer life-expectancies.

---

[16] http://www.cprd.com

There is therefore **a clear public good that can be generated by improving the estimation of individual life expectancy in a pension scheme or retirement product.** Historically this has been achieved using the age and gender breakdown within a portfolio, but, as medical and epidemiological knowledge has increased, additional predictors of longevity have been used such as smoking status, socio-economic circumstances and medical history.

Any item of data that can affect the life expectancy of an individual can be thought of as a ‘risk factor’. The extent to which any particular risk factor, such as smoking or obesity, affects life expectancy can be influenced by interactions between different risk factors. Crude aggregate level analysis of data sets examining the influence of individual factors on mortality rates can give misleading results. Any analysis needs to properly capture the influence of correlation between data items on any outcome, and this is only possible with access to original data where those correlations are present.

Although models fitted to individual level data will usually be more accurate than models crudely constructed using univariable estimates of relative risk, it is also important to test models to determine how reliable they are. This is best done with individual level data, preferably from a source that is independent of the data used for fitting. These regression-type models can only be fitted if there is access to the individual health data, to take account of the correlations and associations between the different data items. Real-world health data sets similar to CPRD, such as ‘The Health Improvement Network’ (THIN),[17] have been used to test predictive models like the QResearch set that were developed using other data sources. QRisk2[18] is a regression model that estimates the 10-year risk of a cardiovascular event. This model is now used routinely in clinical practice across the NHS when making treatment decisions for patients at increased risk of cardiovascular events. It is unlikely that the QRisk model would have been so widely accepted had it not be fitted using a data set representative of the UK population and had it not been externally tested on a separate, but similarly representative, data set.

Other prominent examples of regression models that have been externally validated using individualised data not used for the fitting process include the Framingham cardiovascular risk equations, the UK Prospective Diabetes Survey (UKPDS) model of cardiovascular risk in people with diabetes[19] and the ‘Systematic Coronary Risk Evaluation’ (SCORE) model.[20]

2.2 Equity release from housing for property owners

The House of Lords report *Ready for Ageing?* recommended that: *“People with housing equity should be enabled to release it simply, without excessive charges or risk. The Government should work with the financial services industry to ensure such mechanisms are available, and to improve confidence in them”.*

In England, around 77% of those aged 65 and above own their homes,[21] and most no longer have a mortgage. The total value of homes owned by people age 60 and above in England has been estimated

---

[17] https://www.ucl.ac.uk/pcph/research-groups-themes/thin-pub/database

[18] http://www.qrisk.org

[19] https://www.dtu.ox.ac.uk/riskengine

[20] http://www.heartscore.org.

[21] English Household Survey 2013-14.

to be £1.28 trillion, of which £1.23 trillion is un-mortgaged, compared with £769 billion of savings held by the same group.[22]

Equity release products have been increasing in popularity in the retirement market. They are essentially loans that use the equity in property, usually the family home, as collateral against the loan, allowing the policyholder to continue to live in the home until they move to residential care or die, when the loan is repaid from the proceeds of the sale of the house. Some products offer a last survivor policy, when repayment is further delayed until the second person to be included in the policy, usually a spouse, either dies or moves into a care home.

Loans can be received either as a lump sum, or as regular payments. The amount an individual can borrow from such equity release is dependent on his or her age. Generally, the loan to value ratio is less than 50%, but higher proportions are available at much higher interest rates. Any excess money after sale of the home is left to the estate of the policyholder.

Most policies now carry a "no negative equity" guarantee. This guarantee means that, once a property is sold and purchase taxes and additional fees are paid, then neither the policyholder nor the estate will be required to make any further payments, even if the amount remaining is not sufficient to pay back the loan in full.

There are two main types of equity release product:

- **Lifetime Mortgages** (available to individuals aged 55 and over). These are a type of reverse mortgage, where the policyholder retains ownership of the property against which the loan is raised.
- **Home Reversion** (available to individuals aged 60 and over). The policyholders sell part or all of their property, usually at prices lower than market value, dependent on age, to release equity. Once the policyholder dies or moves into a care home, the property reverts to the insurance company.

The advantages of these products in retirement planning have been outlined in the *Ready for Ageing?* report. Equity release products can supplement retirement income, release equity that is locked in people's homes, allow people to live in their own homes without having to downsize, and provide some certainty with respect to finances. In addition, such loans could be used to pay for care and pay off any other outstanding debt.

Data requirements for equity release products

In order to model the probabilities associated with lifetime mortgages accurately, providers require data on the probability of dying while being a home owner, the probability that a home owner will move into a care home, and the most likely age at which these events will occur. However, these data are very difficult to find.

Mortality rates for homeowners are largely unknown as no standard mechanism exists where such data could be collected. Although the place of death is recorded on the death certificate, many people die in hospital, so it is unclear whether they were still living at home before their final admission. Therefore, equity release providers have to make assumptions about the proportions of homeowners who will die while still holding equity.

Data on the numbers of people entering state-owned care home facilities may be recorded at local authority level, but **these data are not collected at a national level**, and data on private care homes are

---

[22] Wood (2013).

even more difficult to find. If better products are to be provided for those with housing equity, these important data would first need to be collected, and then be made available to private sector providers.

2.3 Specialist housing for older ages

The *Ready for Ageing?* report stated that: "*Many localities have a need for greater provision of more suitable housing for older people, with more support services. The 2006 Wanless Social Care Review reported that 27% of older people would consider specialist housing if it were available. In February 2012, a YouGov poll for Shelter concluded that 33% of people over 55 were interested in specialist housing, which equates to more than six million people".*

A 2012 report by Shelter on housing for older ages has highlighted the limited supply of specialist housing within England.[23] Specialist housing in this context means housing exclusive to people of older ages, which typically includes care and support services and other communal facilities aimed at promoting a greater degree of independence. For the purposes of this paper, we include **retirement villages, sheltered housing and extra care schemes** within its definition.

Using data from the Elderly Accommodation Counsel, the Shelter report estimated that there were 7.3 million 'older households' in England in 2010, defined as households where only people aged 55 and over are resident. This represents more than one-third of all households. The report estimated that there were 533,000 specialist units in England at that time, representing 2% of total housing stock, less than 25% of which were owner-occupied, and primarily consisting of social rented homes provided by local authority or housing associations and bedsits, with many built during the 1960s.

Despite a high demand, just 1% of adults aged 60 and above within the UK are estimated to live in retirement homes, compared with 17% in the US and 13% in Australia.[24]

A 2013 report from Demos found that, of adults aged 60 or over:[25]

- 3.5 million people within the UK (25%) were interested in purchasing a retirement property;
- Over 8 million (58%) were interested in moving; and
- 4.6 million (33%) wished to downsize.

Of the 58% who expressed interest in moving, the report estimated that, if half of them were able to do so, it would free 3.5 million homes and release around £356 billion worth of property. Of these homes, close to 50% have 3 bedrooms and 20% have 4 bedrooms.

Highlighting the potential benefits from the release of housing stock, the report states that "*Apart from the obvious gains to the housing chain, there is robust evidence that retirement housing has a very beneficial effect on older people's health, wellbeing and social networks, and could save health and care services considerable resources. The equity released could help tackle pensioner poverty and have wider economic benefits*".[26]

---

[23] Shelter (2012), p.19.

[24] Ibid.

[25] Wood (2013), p.10.

[26] Wood (2013), p.11.

Given the stated demand for specialist housing and its potential benefits, what are the barriers to the provision of more housing stock? We examine briefly some of the obstacles below.

Obstacles to the supply of specialist housing

"*Retirement housing occupies an uneasy space between residential care and general needs housing and seems to lose out as a result – penalised by general needs planning rules, and misunderstood by social services. Some experts we spoke to suggested that this uneasy position – bringing with it a different and inappropriate set of planning rules, the complexity of coordinating service provision with housing, and a negative attitude among planners – was discouraging new entrants from entering this part of the house building market*".[27]

The supply of new housing for older ages has fallen since the financial crisis of 2008. Build rates have fallen, with 7,000 units built in 2010 compared with 30,500 units in 1989.[28]

The Demos report has described some of the obstacles specific to the development of new specialist housing stock.[29] They include the following:

Commitment at the local level. High-density dwellings tend to be favoured by local planners over the more spacious, low-density housing preferred by older people.[30] Within the specialised housing market, local authorities tend to "*focus on social sector stock and issues (e.g. extra care housing), with few addressing the needs of older owner occupiers or private renters".*[31]

Regulatory environment. Elements within the planning regulations have been blamed by the housing industry for adding an additional cost burden to the development of specialised housing. Examples include the following:

- **Section 106 agreements of the Town and Planning Act 1990**: Designed to offset the impact of new developments, developers of private housing are charged so that local authorities can invest in affordable housing. However, no distinction is made between private specialist housing, with its added inherent costs, and general needs housing.
- **Community Infrastructure Levy** (CIL): A planning charge, CIL is charged as a flat rate per square metre on new housing development. However, depending on the type of specialist housing developed, up to one-third of the floor space may be shared and "*so not sellable*", making it more difficult to recoup the costs.

Building requirements. Issues of location are critical in ensuring a degree of independence for older residents. Developments such as retirement villages need to be located near shops, services and transportation links. Such sites are either harder to find, lie within high value areas, or are in demand for a variety of competing uses, both residential and non-residential. Developers are also put off by the additional land requirements necessary for low density housing.

Public acceptability. As specialist housing may be confused with either public social housing or residential care, the lack of public acceptability can also be a limiting factor.

---

[27] Wood (2013), p. 27.
[28] *Ready for ageing?* p.86.
[29] Ibid, pp. 23-28.
[30] Shelter (2012), p.22.
[31] Ibid, p.24.

Understanding these issues and how they interact with other factors requires access to data that are often not collected or accessible.

Data requirements for specialist housing

"... *it is also crucial to 'address the needs of people over retirement age, including the active, newly-retired through to the very frail elderly, whose housing needs can encompass accessible, adaptable general needs housing for those looking to downsize from family housing and the full range of retirement and specialised housing for those with support or care needs".*[32]

Data are required to help offset some of the market restrictions described above. In particular, providers need a clear understanding of the likely demand for specialist housing over the next few decades based on changing demography and affordability of the homes, and what level of adaptation is likely to be needed to enable older residents to live independently. A number of factors need to be identified and accurately quantified, including the following:

Age and gender profiles. The more elderly population can be categorised into several subgroups with different requirements for property size, social space and visitor guest rooms and additional services.

- Empty nesters: typically aged 55-65, this group may no longer need larger homes to accommodate children.
- Early retirement (Beginning to retire): typically aged 65-75, this group may also prefer a smaller property with some help with house maintenance, and generally want access to a social network, leisure and recreation activities.
- Later retirement (Settling well in retirement): typically aged 75-85, this group generally needs more support and services to keep living independently.
- Care needed: the 85+ age group are less likely to be able to live independently without additional care.

Data are needed to predict the population size in each of these dependency groups if specialist housing supply is to match demand. Data from the UK census contain some invaluable information for this purpose. However, more granular information will improve estimates for housing needs.

Marital and family status. Marriage and companionship can offer protection against mortality and morbidity and may extend the span of independent living, so data on cohabitation rates may be able to inform estimates of life expectancy and support needs.

Constraints in activity. Reduced abilities to undertake activities of daily living reflect needs for greater support. Various tools can measure Instrumental Activities of Daily Living (IADL), which includes the ability to use the phone and undertake shopping and housekeeping tasks, and Activities of Daily Living (ADL), which include washing, dressing, and getting in and out of bed.

Data on the proportion of the elderly population with each grade of activity constraints could help plan the appropriate level of modifications to specialist housing. These may be further differentiated by socio-economic group.

Measures of disease and co-morbidity. An accurate assessment of morbidity, especially the proportion of the older

---

[32] *Ready for Ageing?,* quoting from Department for Communities and Local Government (2012) National planning policy framework, p.54.

population with diseases such as dementia, Parkinson's disease or cancer, could help plan the need for residential care. Data on disease prevalence and how this varies in relation to individual risk factors are necessary for such planning, especially if further differentiated by socio-economic group.

Measures of lifestyle risk factors. Risk factors are key determinants of morbidity and mortality, yet their prevalence among the older population may not be well understood. Risk factor rates such as smoking and alcohol consumption among older adults, again with further differentiation by socio-economic group, is important for accurate modelling of need.

Rates of disease progression. Most adults can live independently with early, mild chronic disease, but may need residential care when more severely affected. The rate of progression between morbid states of disability, severe disease, recovery or death, and different trajectories in subpopulations, is often poorly understood. Anonymised individual data are necessary to determine the pattern of disease progression in subgroups with a disease.

As we have discussed in previous sections, **many of these data items are either not collected, or not accessible to the private sector at the required individual level**.

2.4 Social care

"*Currently, individuals cannot protect themselves against the risk of very high care costs by pooling their risk. In areas such as motoring and housing, people buy private insurance to pool their risk and cover themselves against exposure to high costs. For health care, the NHS pools risks by providing social insurance to everyone; for care costs however, the state does not provide universal support and people are unable to take out private protection. This is the only major area in which everyone faces significant financial risk, but no one is able to protect themselves against it*".[33]

The impact of a rapidly ageing population has highlighted the growing need for adult social care. Projections from the ONS show a doubling of the number of those aged 85 and above within 20 years; with the number of centenarians projected to increase from 14,000 in 2013 to 111,000 in 2037. Furthermore, analyses based upon historical data from the UK suggest that, while life expectancy has increased, healthy and disability-free life expectancy has not kept pace.[34] The demand for social care is therefore expected to rise dramatically.

The provision of adult social care includes formal and informal home-based and residential care services. We focus on adult residential or long-term care (LTC) services as we feel the delivery of such services has lagged. To address the shortfall, we examine the requirements necessary for the development of a market to insure against catastrophic LTC costs.[35]

Paying for residential social care

A 2013 report from the King's Fund has noted the continuing pressure on the public social care system.[36] In contrast to past decades, the report estimates that 92% of residential care and nursing home places are now supplied through private and voluntary providers, with expectations of some level of self-funded care.[37] Faced with an increasingly ageing population, the

---

[33] Dilnot report (2011), p.13.

[34] Institute and Faculty of Actuaries (2014), p.13.

[35] For the consumer, a number of pension or protection based products are available with potential to offer some protection against future LTC costs including income drawdown; variable annuities; immediate needs annuities/equity release.

[36] Humphries (2013).

[37] Ibid, p.5.

retreat of the public sector in the funding and provision of residential social care has, for many, left a void in the ability to adequately finance their care in the latter years of life.

In order to protect the individual from excessive social care costs, the 2011 Report of the Commission on Funding of Care and Support (known as the "*Dilnot report*") proposed a social limited liability insurance model with shared costs between the individual and the state. A lifetime financial cap on costs and means-testing for social care services were proposed so that a greater number of people would benefit from public funding.

Based in part on the recommendations of the Dilnot report, the Care Act of 2014 incorporated the new funding model for adult social care and introduced limits regarding eligibility and payment, including:[38]

- application of a £72,000 cap on the amount a person has to pay for their social care during their lifetime;[39]
- an increase in the threshold below which people are eligible for local authority financial support towards care costs for means-testing. For homeowners, the upper capital limit would increase from £23,250 to £118,000; for others, it would rise from £27,000;[40]
- eligibility criteria set at the national, rather than local, level; and
- a personal contribution of at least £12,000 a year towards general living expenses in residential care.

However, in July 2015 the government announced a delay until April 2020 in the implementation of the lifetime cap on social care costs. Concerns had been raised by the Department of Health that proposals to "*cap care costs and create a supporting private insurance market were expected to add £6 billion to public sector spending over the next 5 years*",[41] and that a period of consolidation was not the appropriate moment "*to be implementing expensive new commitments such as this, especially when there are no indications the private insurance market will develop as expected*".[42]

The deferment of the cap was made largely at the behest of local authorities, who asked that the allocated funding be used more generally in addressing the current crisis and shortfall in social care services. The announcement did not state what the level of the 2020 lifetime cap or means test will be.[43]

Recent estimates from the Institute and Faculty of Actuaries (IFoA) show that people on average will be expected to pay up to £140,000,including living expenses, before enforcement of the cap.[44] The IFoA estimates that only 8% of men and 15% of women will in future be likely to reach the level of the cap.

Serious concerns over the financing and provision of adult social care therefore remain. The shortfall in public sector support for social care provision serves to underscore the need for private sector engagement and collaboration to grow and sustain a private insurance market for LTC.

We submit that, **for the private sector to bear the burden of risk, either in full or partially, comprehensive and appropriate data must be available**. We highlight some of the issues below.

---

[38] Adapted from Kalsi (2015).

[39] Only care payable at the local authority rate will accrue towards the lifetime contribution cap.

[40] Level of personal assets at which a person would be eligible for help towards residential care costs regardless of the lifetime cap.

[41] Lord Prior of Brampton (2015).

[42] Ibid.

[43] The introduction of a 'brokering' system for self-funders and a new appeals system has also been delayed.

[44] IFoA (2014), p.6.

Long-term care (LTC) market failure

The *Ready for Ageing?* report examined the feasibility of developing a specific insurance market to cover LTC costs.[45] It describes the market failures – supply and demand sides – and uncertainty related to the provision of LTC insurance. The report highlights the lack of consumer knowledge, consumer misconceptions or behaviours and provider/insurer uncertainty as principal limiting factors.

Demand: lack of consumer knowledge. Current public attitudes reflect the **widespread misconception that the provision of long-term social care will be free,** in the same way that NHS healthcare is provided free at the point of contact, thereby making it difficult to consider the purchase of a specialised insurance product. This misconception is further compounded by a lack of adequate predictions regarding disability-free life expectancy, the likelihood of future social care needs and the availability of current assets and pensions to offer protection.

Supply: uncertainty for providers. The barriers towards the formation of a sustainable market for LTC insurance have been demonstrated in the US, where the market is currently in steady decline. Within the US, the number of LTC policyholders has shrunk as providers raise premiums to cover larger than anticipated care costs that have arisen, for example, by under-estimating care cost inflation and the incidence and severity of disability.

LTC pricing assumptions are partly based on forecasts of disease incidence rates, claims continuance and the proportion of care costs spent at the time a claim occurs. **The larger than anticipated costs reflect the lack of data to support more accurate projections**. This includes:

- **Lack of disability data**. Anticipating the onset of morbidity leading to disability for an individual represents one of the more complicated aspects of a consumer product. Estimates should incorporate disability patterns including the progression of "*varying states of disability severity (and death) and recovery rates from disability, neither of which has been adequately analysed by the LTC insurance community*".[46] As LTC products are relatively new, little credible data exist to support the refinement and improvement of the coverage offered, such as established LTC morbidity tables.
- **Uncertainty inherent in the long time horizons**. For the provider, the relative increase in time horizon carries a high degree of uncertainty over the provision of LTC insurance. The *Ready for Ageing?* report states that "*although an insurer may know the likelihood that a person entering care today will stay for a certain length of time, such probabilities might change substantially over the period of an insurance contract, especially if the contract is entered into prudently early*".
- **Adverse Selection**. As with the health insurance and annuity markets, issues of adverse selection can occur, as consumers who expect greater utilisation costs would be more likely to enrol.

Data requirements for social care

---

[45] For the consumer, a number of pension or protection-based products are available with the potential to offer some protection against future LTC costs. They include the following: income drawdown, variable annuities, immediate needs annuities/equity release.

[46] Rubin et al. (2014), p.13.

The high degree of uncertainty over the provision of LTC insurance, compounded by the lack of data, has already been noted in the Dilnot report. Examining the potential for the private sector to insure the risk associated with LTC, the report concluded "*there is currently too much uncertainty involved for the private sector to take on the full risk*".

Quantification of disability and morbidity, including future needs for residential care, would **at the very least** include the following:

- **Measures of frailty**. Examples include the Edmonton Frail Scale[47] which incorporates measures for cognition, nutrition and hospital admissions within a year.
- **Measures of Daily Living (DL)**. Data on how such measures of disability vary across socio-economic group would help price LTC products appropriately for each individual.
- **Measures of disease and co-morbidity**. Although data on mortality from specific disease are readily available, the prevalence of chronic diseases such as dementia, Parkinson's disease or cardiovascular disease is harder to find, especially differentiated by socio-economic group.
- **Rates of progression** between morbid states of disability, severe disease, recovery or death would also be helpful to predict the level of care likely to be needed over time.

This section of the paper has shown that **access to anonymised, individual level data on health and social care needs are essential for adequate provision of suitable products for the elderly.** Yet such data may not be collected and, if collected, confusion over the legal requirements for data protection may have unnecessarily limited access to the data by the private sector. In the following sections, we discuss the relevant legislation, and the contradictions and confusion it has caused.

---

[47] Rolfson et al. (2006).

Section 3. Legislations relevant to the provision of data for the public good

Current legislation supports the provision of national statistics to promote economic success, health and wellbeing. To better understand the legislative intent of the policy makers, the section below summarises the elements of data-related legislation from the UK or European Union.

It is important to distinguish between legislation specific to the collection and use of personal data and legislation for the collection and dissemination of national or population data. In addition, consideration must be afforded the common law duty of confidentiality that protects private information, including personal, commercial and government information, from disclosure. This includes information that:

- is not in the public domain; and
- was "*imparted in confidence in the context of a confidential relationship*".[48]

Protection against disclosure may be waived, however, by consent or if deemed within the public interest.[49]

Where applicable, we highlight the publication of the Codes of Practice for the appropriate authority. The Codes of Practice both interpret and make operational the legislative intentions and expectations of the policy makers and are enforceable by law.

Further details of the main legislation and Codes of Practice are reported in the Appendix to this paper.

3.1 Personal Data

Data Protection Act, 1998 / European Data Protection Directive (95/46/EC). The Data Protection Act represents a key element of UK legislation governing the protection of personal data. The Act brought British law into line with that of the 1995 EU Data Protection Directive,[50] and set out the eight data protection principles[51] which today comprise the bedrock for personal data protection.

Human Rights Act 1998 / European Convention on Human Rights. The Human Rights Act (UK) safeguards the right to respect for privacy and family life under Article 8 of the European Convention of Human Rights (ECHR). As noted in a 2014 report from the Law Commission, data protection, including personal information such as name, address and date of birth, is included under the ECHR "*as part of the qualified right to privacy and family life*".[52] Any decision by a public body on the sharing of data therefore requires an assessment of its impact on a person's right to privacy and family life.

Health and Social Care Act 2012. The Act addresses a range of issues relating to health and social care and gives effect to

---

[48] Law Commission. Law Com No 351. Jul. 2014. Data sharing between public bodies: A scoping report. Law of confidence. 1.62, p.16.

[49] Law Commission. Law Com No 351. Jul. 2014. Data sharing between public bodies: A scoping report. Law of confidence. 1.63, p.16.

[50] 1995 EU Data Protection Directive (95/46/EC).

[51] Schedule 1. Part 1. The Data Protection Principles. The Data Protection Act 1998 (c.29)

[52] Human Rights Act 1998 and the European Convention on Human Rights. No. 3.55. Law Commission. Data sharing between public bodies. A scoping report, p.62.

the policies set out in the White Paper *Equity and Excellence: Liberating the NHS* (2010). Although its main aims are to change how NHS care in England is commissioned, the Act also sets out provisions for information standards. Increased powers are given to the HSCIC to establish information systems for the collection and analysis of data. The HSCIC is empowered to publish a code of practice for the collection, analysis, publication and other dissemination of confidential information connected with the provision of health service or adult social care in England.

Health and Social Care Information Centre (HSCIC) Code of Practice on Confidential Information 2014. The HSCIC Code of Practice on Confidential Information (December 2014) sets out its criteria for the handling of confidential personal data. The HSCIC is permitted to "*use its general dissemination powers where the intended purpose is in connection with the provision of health care or adult social care, or the promotion of health*".[53] A wide range of activity including commissioning, healthcare provision and epidemiological research that supports the public interest is included. However, **the dissemination of data for "*solely commercial intended purposes*", including commercial insurance, is prohibited** in the Code of Practice.[54]

Care Act 2014. The Care Act (England) contains five parts and eight schedules relating to adult care and support. The sections of relevance to this paper include Parts 1 (Adult Social Care) and 4 (Amendments to the Health and Social Care Act 2012).

- ***Part 1*** sets out the legal framework for the provision of adult social care in England and consolidates a number of recommendations from several reports and white papers including *Fairer care funding*: *The report of the Commission on funding of care and support* (July 2011, the *"Dilnot report"*), which implements changes put forward by the Commission on the Funding of Care and Support; and *Adult social care* (May 2011), which provides the Law Commission recommendations on the consolidation and modernisation of existing care and support law.[55]
- **Part 4** amends sections of the Health and Social Care Act 2012 as it relates to the HSCIC, including further clarification on the dissemination of information for the purposes of health and adult social care provision or the promotion of health[56], and added stipulation for "*the need to respect and promote the privacy of recipients of health services and of adult social care in England*".[57]

EU Data Protection Framework and Regulation (in progress). The European Commission has set about the task of reviewing the general EU statutory framework for the protection of personal data. Some of its policy objectives are to:[58]

---

[53] Ibid p.11.

[54] Ibid p.11.

[55] Law Commission 326, HC 941. May 2011.

[56] For Section 261. Other dissemination of information. The following clause has been added: "*But the Information Centre may do so only if it considers that disseminating the information would be for the purposes of – (a) the provision of health care or adult social care, or (b) the promotion of health*".

[57] The item "*the need to respect and promote the privacy of recipients of health services and of adult social care in England*" is added after para. (c) of Section 253(1) (General duties).

[58] Reform of the data protection legal framework. Update 23/10/2014.http://ec.europa.eu/justice/data-protection/review/index_en.htm Accessed 09/06/2015.

- modernise the EU legal system for personal data protection;
- strengthen individual rights; and,
- improve the clarity and coherence of the EU data protection rules for personal data.

The plans to unify data protection in the EU within a single law are encapsulated in the Data Protection Regulation (2012/011(COD)), which considers current trends such as globalisation, cloud computing and the use of social media. After numerous amendments, the Commission expects to adopt the regulation by 2015/16, plus a transition period of two years after which the regulation will come into immediate effect in all 28 member states.

Notable items include an expectation that the definition of personal data can encompass: "*any information relating to an individual, whether it relates to his or her private, professional or public life. It can be anything from a name, a photo, an email address, bank details, posts on social networking websites, medical information, or a computer's IP address*".[59]

If passed in its current form, the Regulation will have a significant and wide-ranging impact on the collection, use and storage of personal data across the EU member states.

Other Acts. A number of other legislations provide stipulations about confidentiality for specific populations. These include:

- ***Mental Health Act 1983, amended 2007.*** The Mental Health Act sets out the conditions under which a person with a mental health disorder can be admitted to hospital, detained or treated without their consent, for the protection of other people. The Act does not include specific requirements about confidentiality. The common law requirements for confidentiality may be irrelevant where mental illness means that informed consent for disclosure cannot be given, and health or social care professionals may be able to disclose personal information where they believe it is in the best interest of the person or the public.
- ***NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000.*** This Act, and the National Health Service (Venereal Disease) Regulations of 1974, stipulate that health authorities providing sexual health services must not disclose any information that could identify a patient being treated for a sexually transmitted infection, unless such disclosure will help a healthcare practitioner manage the disease or prevent its spread.
- ***Abortion Act 1967.*** The Abortion Act states that patients seeking abortion, both adult and child, have the right to confidentiality that cannot be overridden other than in exceptional circumstances, such as where rape or sexual abuse is suspected.
- ***Children Act 2004.*** In contrast to other legislation that aims to protect the confidentiality of individuals, the aim of the Children Act is to facilitate appropriate information sharing to safeguard vulnerable children. Section 10 of the Children Act requires all local authorities and partner agencies to introduce and monitor information-sharing processes. The Act states the need to obtain informed consent from a person under the

---

[59] EC Press release.

age of 18 years if they have the emotional and intellectual competence to understand the consequences of such consent and alternative options, while accepting that sharing information without consent may be justified to protect the child.

3.2 Population Data

Statistics and Registration Service Act, 2007 (c.18). Mostly concerned with the structure of the organisations that deliver national statistics and registration services, the Act creates an independent Statistics Board (UK Statistics Authority or UKSA) as a non-ministerial department accountable only to Parliament, which provides the top layer of governance for the ONS.[60] Empowered by the Act, the UKSA has a statutory responsibility to promote and safeguard the production and publication of official statistics that serve the public good. It places an obligation on the UKSA to publish a Code of Practice against which all of ONS's products and the 'national statistics' will be assessed for compliance.

Code of Practice for Official Statistics, 2009. The Code establishes a 'cornerstone' for the framework provided by the Statistics and Registration Service Act (2007), and serves to establish common standards across a decentralised statistical service. Compliance with the Code is a statutory requirement for all public bodies that produce official statistics. The Code recognises that **the dissemination of official statistics should meet the requirements of informed decision-making by various stakeholders, including business**. It contains eight principles and statements of associated practices.

Relevant aspects of the Code include the following:

- Identification of business as a member of the user community.[61]
- Establishment of the public interest.[62]
- Establishment of data security and confidentiality.[63]

Better Statistics, Better Decisions: Strategy for UK Statistics 2015-20. Published in 2014, the UK Statistics Authority 5-year strategy (2015-20) reiterates a "*statutory objective of promoting and safeguarding the production and publication of official statistics that serve the public good".*[64] New opportunities and an emphasis on data sharing and 'open data', such as embedding the principles of open data to official statistics, are highlighted within the strategy, which also stresses that there is a need for "*developing partnerships across the private and public sectors".*[65]

---

[60] Replacing government ministers.

[61] Principle 1 (Meeting the user needs) states that the "*production, management and dissemination of official statistics should meet the requirements of **informed decision-making** by government, public services, **business**, researchers and the public*".

[62] Principle 3 (Integrity) emphasises that "*At all stages in the production, management and dissemination of official statistics the **public interest should prevail***".

[63] Principle 5 (Confidentiality) states that "*private information about individual persons … compiled in the **production of official statistics is confidential and should be used for statistical purposes only***".

[64] UK Statistics Authority (2014).

[65] Ibid, p.5.

Section 4. Unintended consequences of the legislation

4.1 Confusion over complex legislation on data provision

The Law Commission’s review of data sharing between public bodies identified the “*piecemeal and ad hoc way*” in which existing data legislation has developed.[66] The report noted that “*this has meant that the law has developed without consistent oversight and scrutiny, resulting in a complex web of statutory provisions*”.[67] As a result, the largely unintended effects have included[68]:

- significant problems in understanding the Data Protection Act 1998 and other law governing how information may be shared;
- wide variation between people and across time in the interpretation of the expressed and/or implied meaning of the statutory provisions; and
- unclear and sometimes conflicting guidance.

Confusion over the interpretation and implementation of the legislation can delay or inhibit the provision of services that support the interest or good of the public. We explore further the notion of the ‘public good’ below.

4.2 Definition of the ‘public good’

UK statutes regarding the publication or dissemination of national statistics have made reference to the service of the ‘public good’ within the Acts and Codes of Practice specific to the UK Statistics Authority and the ONS. They include the following:

UK Statistics Authority (UKSA). The independent Statistics Board’s objectives include the production and publication of official statistics that serve the public good or public interest. These two terms are often conflated but do not necessarily refer to the same set of circumstances. Public good, as an economic term, implies some economic gain to society, and so may well include acts undertaken by the private sector.

The public interest is codified within the UK Statistics Authority’s Code of Practice for Official Statistics ed.1. (2009) in particular Principle 1, Meeting user needs. This states that “*The production, management and dissemination of official statistics should* ***meet the requirements of informed decision-making by government, public services, business, researchers and the public*”**.

Office for National Statistics (ONS). Criteria used by the ONS to screen applications for access to sensitive data, including **personal** information, include an assessment for “*statistical research that serves the public good*”. Elaborating on Sections 7(1) and 7(2) of the 2007 Statistics and Registration Act,[69] the ONS defines studies that serve the public good as research that, among other things:[70]

“*1.3. informs debate, decision making and research both within government and by the wider community;*
1.4. provides an objective perspective of the changes taking place in national life …
1.5. offers a window on the work and performance of government … in every area of public policy and allowing the impact of public policies and actions to be assessed; and
1.6. assists the Government in its work”.

---

[66] Law Commission (2014). No.4.17, p.75.
[67] Ibid. Section 4.17 p.75.
[68] Ibid, p.3.
[69] And using the Principles and Guidelines of Good Practice from the UN Economic Commission for Europe (UNECE).
[70] Glossary of Terms. “Public Good.”Approved researcher access application form. ONS.

Within its 2015-20 strategy, the UKSA has described the 'public good' as including the following activities:[71]

- informing the public about social and economic matters;
- assisting in the development and evaluation of public policy; and
- regulating quality and publicly challenging the misuse of statistics.

Further elaboration of the 'public good' was provided by the UK Data Service, which defined it as an activity that widens access to information sourced from the Service and has "*social and economic benefit*".[72]

However, a demarcation between the commercial, or private, and non-commercial, or public, use of data has also been established with, for example, support of the public good provided only under the definition of non-commercial public sector use.[73] Furthermore, in the December 2014 publication of its Code of Practice, the HSCIC states that it: "*can only use its general dissemination powers where the intended purpose is in connection with the provision of health care or adult social care, or the promotion of health … **not for solely commercial intended purposes such as for commercial insurance***".[74]

Close collaborations between the public and private sectors already exist within healthcare, with the outsourcing of services throughout the supply chain. We argue that, as the pensions and other insurance industries have been challenged by the House of Lords to innovate and develop retirement products to safeguard the welfare of a rapidly ageing population, **the provision of services such as pensions, equity release, elderly care insurance and specialist housing by the private sector or public-private sector partnerships ultimately implies support for the 'public good'.** Section 2 of this report has discussed those areas where the House of Lords sub-committee has identified the need for greater collaboration with the private sector.

4.3 Public acceptance

"*The experience of care.data starkly exposes an enduring truism about the limits of law: legal authority does not necessarily command social legitimacy. A parliamentary majority may allow legislation to be passed, but that does not equate to a societal seal of approval … patients need to have the confidence that their medical records will be held securely, anonymised appropriately, and that secondary use of this personal data is in the public interest*".[75]

An example of problems that can arise from disagreements about appropriate sharing of data is the NHS care.data project. Care.data is a collection of individual patient records, and, unlike other data sources such as the Hospital Episode Statistics or the CPRD database, it tracks patients across both primary and secondary care. It is therefore a good example of the kind of data that this paper has been calling for in Section 2, allowing disease progression to be mapped and the impact of risk factors and treatments to be assessed in different subpopulations.

In 2014, controversy arose when a mis-managed marketing strategy led to confusion about the purpose of the database, and fears that personalised data would be sold to private companies for commercial gain. As a result of this poor communication the project was postponed. Information available to the public at the time of writing this report only

---

[71] UK Statistics Authority (2014), p.3.
[72] Ward (2013), Slide 7.
[73] Ibid.
[74] HSCIC (2014), p.11.

[75] Carter et al. (2015).

mentions the use of the data to guide healthcare, public health and social care services,[76] suggesting that access to this potentially invaluable source of anonymised data by the private sector may be restricted.

The existing situation is therefore causing confusion and is a barrier to the effective development of products to better support the elderly population by the private sector.

Based on common law rather than statute, interpretation of the law in the UK can be inherently uncertain, and this is highlighted by the confusion over disclosure of the types of data required by the private sector. Each new piece of legislation has addressed some previous concerns, but at the risk of adding new contradictions or uncertainty.

We believe that many of these issues might be resolved by the establishment of a **coherent legal structure and entity to govern the collection, management and dissemination of public statistics, data and information to support the public good.**

Additionally, the private sector should seek to increase confidence and gain trust with the public regarding the use of data. This might be done through greater transparency by:

- establishing a code of practice to ensure confidentiality, disclosure and clear purpose relating to the use of data, with a clearly defined structure for strict sanctions that are acceptable to all stakeholders;
- improving communication with the public to ensure emerging issues are discussed and dealt with; and
- raising awareness on how public data can be used to provide solutions to challenges posed by an ageing population and longevity.

---

[76] http://www.nhs.uk/NHSEngland/thenhs/records/healthrecords/Pages/care-data.aspx

Section 5. Discussion and recommendations

5.1 Discussion

A combination of rising life expectancy and falling fertility has led to an ageing population in the UK. The nation will see unprecedented challenges in the provision of pensions, housing, healthcare and social care. The resolution of these challenges will need collaboration between the public and private sectors as they work in tandem to make informed decisions for public policies and commercial activities.

These decisions can only be made effectively if they are based on evidence from statistics, anonymised data and other information about the population that is currently held by public bodies. The increase in computing power and availability of data held by public bodies presents opportunities for research and mathematical modelling that could help improve or develop services for the ageing population.

The pensions industry has been helping the public manage longevity risk through financial products such as annuities. However, financial products and political agendas change over time. For example, in the Summer Budget of 2015, the UK government reiterated its intention for existing annuity holders to have the freedom to sell their annuity income in return for cash. This has raised concerns that a growing proportion of the elderly will run out of income to support their increasingly long retirements. The industry and government are working towards a more robust solution to develop a market for retirement income transactions to be implemented in 2017.

The determination of the prices or values of annuities requires assumptions about how long annuity holders can expect to live. The availability of health data for anonymised individuals could contribute to scientific research to determine how longevity is associated with health-related factors including age, health status, risk factors and diseases. The results could contribute to assessing the value of annuities.

Anonymised health data could also be used to test existing mathematical models that estimate mortality or survival trends of annuity holders.

The pensions industry would be able to deliver greater public benefit with access to anonymised, individual level data such as the CPRD and BIOBANK.[77] However, the current, narrow interpretation of 'public good' appears to prohibit access, with the potential consequence of increased risk, increased cost and more restricted access to pension products.

We argue that, **better access to individual-level data by the private sector could add to the public good** by;

- improving the estimation of individual life expectancy in a pension scheme or retirement product which has historically been based solely on age and gender, but could be calculated more accurately with the use of anonymised, individual data;
- understanding the relationship between risk factors such as smoking status and obesity to provide a better and more realistic

---

[77] http://www.ukbiobank.ac.uk/

estimate of life expectancy and social care needs; and
- testing of models used by the finance sector, as is already successfully done for those regularly used by clinicians.

Access to data sources would enable more accurate, and hence fairer, risk assessments about any specific and well-identified group of individuals.

The financial services industry has been urged to provide solutions to help older home owners access the money locked up in their properties. Examples of currently unavailable information that could help refine the pricing of equity-release financial products include the following:

- mortality and survival rates of homeowners of various socio-economic circumstances and health status;
- data tracking how morbidity and disability change with ageing, and how these affect the need for, and timing of, care home use; and
- incidence of care home entry of various sub-populations, such as different age and gender groups, people in different socio-economic circumstances, and those with different health status, morbidity and risk factors.

The housing market is delivering much less specialist housing for older people than is needed. Central and local government, housing associations and house builders urgently need to plan how to ensure that the housing needs of the older population are better addressed. Information and statistics are needed to answer some crucial questions for planning and building, for example:

- What are the phases of accommodation needs, from mid-life (empty nesters, around age 55) onwards?
- What are the characteristics of people in each of these phases?
- What facilities are needed to support independent living and provide adequate care at each phase?
- Where do they need the infrastructure or services to be located?

Answering these questions would help design infrastructure and services to meet the changing demands of the population.

The information required for decision making about the provision and pricing of specialist housing includes data on the following topics:

- disease progression in different subgroups, with data on how quickly people with a particular disease develop disability and either die or need long-term care;
- health care costs to estimate maintenance fees; and
- data to establish the contribution of specialist housing for the elderly on the surrounding economy, and how, by better supporting independent living in the elderly, specialist housing might reduce the burden on health and social care services.

The previous sections of this report have shown that there is considerable overlap in the data needed to inform the provision of adequate services for the ageing population. Essentially, **providing retirement income such as annuities, appropriate specialist housing and predicting health and social care**

needs, all depend on an accurate assessment of current and future lifespan of an individual as well as disease progression that describes the need for additional support over time.

Although aggregated data may be available, the **most accurate modelling of mortality and morbidity progression requires a degree of granularity that may not be available to the private sector**, even though identifiable personalised data would not be needed. In particular, anonymised individual-level data, to reflect the range of socio-economic classes, combinations of risk factors and comorbidities, would allow more reliable estimation of how long any individual could be expected to need specialist housing, or will need to draw an enhanced annuity, or what his or her social care needs are likely to be.

We have observed that some of the required information is not available for either the public or private sectors, because statistics are not collected systematically. A good example is the gap in data on the rate at which people in different groups need, and receive, care home support.

We have also observed that some information is available but not easily accessible by segments of the private sector. An example is the provision of HSCIC-managed anonymised health data of individuals with various risk factors and diseases, which could be used for mathematical modelling of longevity risk by insurance companies. In this example, the purpose of data provision may be considered for the "public good", hence satisfying the intent of Statistics and Registration Service Act 2007 (see Appendix 1). But it may not satisfy the HSCIC remit of data provision for stakeholders *"providing health and social care and promoting health"*, as insurance companies don't provide health and social care directly.

Taken together, we observe that there is much opportunity for the public and private sectors to work together to resolve challenges posed by the ageing population. The provision of necessary statistics, anonymised data and information will contribute to important decision making. However, various pieces of legislation on information provision have emerged separately, with the unintended consequences of adding complexity and confusion for information providers and users. Also, new statistics, anonymised data and information held by public bodies are required if services and products are to be provided to meet emerging challenges.

To improve the provision of publicly-held information for decision making by both the public and private sectors, we put forward four recommendations.

5.2 Recommendations

1. We recommend the formation of a coherent and publicly acceptable legal structure and entity to govern the collection, management and dissemination of public statistics, data and information to support the public good.

- We welcome the Law Commission's recommendation that *"a full law reform project should be carried out in order to create a principled and clear legal structure for data sharing, which will meet the needs of society"*.
- We propose that the reform should include the provision of statistics,

information and data for private sector industries that carry out commercial or non-commercial activities for the public good, rather than exclusively focusing on public services.

2. We recommend that the 'public good' be defined in a way that includes any activity that benefits society or the economy, particularly where that activity is aligned with public policy.

- The lack of a clear definition of the term 'public good' in relation to existing legislation, and uncertainty in its interpretation, is impeding access to information, statistics and data. This could lead to missed opportunities to develop improved services or products for the public.

3. We recommend that strategies are employed to improve the appropriate access of both the public and private sectors to all publicly-funded data, information and statistics, while protecting the privacy of individuals and the public interest. These might include:

- principle-based definitions of the levels of granularity of anonymous data that do not require any restriction on access;
- licensed third-party data warehouses that can analyse sensitive data for other organisations;
- software that enables aggregate analysis of sensitive data without allowing access at the individual level; and
- the UK Statistics Authority extending the remit of its Administrative Data Research Network to the private sector.

4. We recommend that private sector and public bodies are included in discussions to specify what public data and information are needed for the benefit of society and the economy.

- The private sector should be actively encouraged to join Statistics User Fora that are organised by the Royal Statistical Society.
- The private sector should be encouraged to participate in consultations and reviews about the collection and use of statistical databases.

Section 6. Bibliography

All Party Parliamentary Group on Housing and Care for Older People. The affordability of retirement housing. http://www.demos.co.uk/files/Demos_APPG_REPORT.pdf?1415895320

Ball M. et al. (2011). Housing markets and independence in old age: Expanding the opportunities. University of Reading. http://centaur.reading.ac.uk/24443/1/HousingMarketsinOldAge.pdf

Barnett K. et al. (2012). Epidemiology of multimorbidity and implications for health care, research, and medical education: A cross-sectional study. Lancet; 380(9836):37-43. http://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60240-2/abstract

Brodbeck S. (2015). Dilnot reforms fail to spark long-term care market. Money Marketing. http://www.moneymarketing.co.uk/dilnot-reforms-fail-to-spark-long-term-care-market/

Butland B, Jebb S, Kopelman P, McPherson K, Thomas S, Mardell J, et al. Tackling Obesities: Future Choices – Project Report 2nd Edition. Government Office for Science; 2007. 2nd Edition. https://www.gov.uk/government/publications/reducing-obesity-future-choices

Caldicott F. (2013). Information: To share or not to share? The Information Governance Review. Crown Copyright. http://webarchive.nationalarchives.gov.uk/20130805112409/https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/192572/2900774_InfoGovernance_accv2.pdf

Care Act 2014. Chapter 23. London: The Stationary Office. http://www.legislation.gov.uk/ukpga/2014/23/pdfs/ukpga_20140023_en.pdf

Care Act 2014. Explanatory notes. http://www.legislation.gov.uk/ukpga/2014/23/notes/data.pdf

Carter P. et al. (2015). The social license for research: Why care.data ran into trouble. J Med Ethics; 41:404-09. http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4431337/pdf/medethics-2014-102374.pdf

Children Act 2004. London, The Stationary Office. http://www.legislation.gov.uk/ukpga/2004/31/contents

CMI Working Paper 65. (2013). Analysis of the mortality experience of pensioners of self-administered pension schemes for the period 2004-2011.

Comas-Herrera A. (2013). Barriers and opportunities for private long-term Care insurance: What can we learn from other countries? Presentation based on Comas-Herrera A. et al. 2012. Barriers and opportunities for private long-term care insurance in England: What can we learn from other countries? http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/AXARF-Comas.pdf

Data Protection Act (1998). Chapter 29. London: The Stationary Office. http://www.legislation.gov.uk/ukpga/1998/29/pdfs/ukpga_19980029_en.pdf

Department for Communities and Local Government. (2012). National planning policy framework. Crown Copyright. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/6077/2116950.pdf

Dilnot A. (2011). Fairer care funding. The report of the Commission on Funding of Care and Support. http://webarchive.nationalarchives.gov.uk/20130221130239/https://www.wp.dh.gov.uk/carecommission/files/2011/07/Fairer-Care-Funding-Report.pdf

EC Press release. Commission proposes a comprehensive reform of data protection rules to increase users' control of their data and to cut costs for businesses. http://europa.eu/rapid/press-release_IP-12-46_en.htm?locale=en

English Household Survey 2013-14. https://www.gov.uk/government/statistics/english-housing-survey-2013-to-2014-headline-report;

European Commission. COM(2012) 11 final. 2012/0011(COD). Jan 2012. Proposal for a regulation of the European Parliament and of the Council on the protection of individuals with regard to the processing of personal data and on the free movement of such data (General Data Protection Regulation). http://ec.europa.eu/justice/data-protection/document/review2012/com_2012_11_en.pdf

European Council of Human Rights. Council of Europe. (1950). European Convention on Human Rights. http://www.echr.coe.int/Documents/Convention_ENG.pdf

European Parliament and the Council of the European Union. (1995). Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data. http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:31995L0046&from=en

Fernandez J-L, Forder J. (2011). PSSRU Discussion Paper 2771. Impact of changes in length of stay on the demand of residential care services in England: Estimates from a dynamic microsimulation model. http://www.pssru.ac.uk/pdf/dp2771.pdf

Habibi S, Mason S. Department of Health. (2014). Presentation to the NCAS Conference.

Health & Social Care Information Centre. (2014). Code of practice on confidential information. Version 1.0. http://systems.hscic.gov.uk/infogov/codes/cop/code.pdf

Health and Social Care Act 2012. Chapter 7. London: The Stationary Office. http://www.legislation.gov.uk/ukpga/2012/7/pdfs/ukpga_20120007_en.pdf

House of Lords Select Committee on Public Service and Demographic Change. Report of Session 2012-13. March 2013. Ready for ageing? http://www.parliament.uk/business/committees/committees-a-z/lords-select/public-services-committee/report-ready-for-ageing/

Hughes N. Shelter. Apr 2012. A better fit? Creating housing choices for an ageing population. http://england.shelter.org.uk/__data/assets/pdf_file/0005/427730/Policy_report_A_better_fit.pdf

Human Rights Act 1998. Chapter 42. London: The Stationary Office. http://www.legislation.gov.uk/ukpga/1998/42/pdfs/ukpga_19980042_en.pdf

Humphries R. The King's Fund. (2013). Paying for social care. Beyond Dilnot. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_summary/social-care-funding-paper-may13.pdf

Information Commissioner's Office (2012). Anonymisation: Managing data protection risk. https://ico.org.uk/media/for-organisations/documents/1061/anonymisation-code.pdf

Institute and Faculty of Actuaries, Pensions and Long Term Care Working Party. (2014). How pensions can help consumer needs under the new social care regime. http://www.actuaries.org.uk/events/one-day/how-pensions-can-help-meet-consumer-needs-under-new-social-care-regime

Kalsi K, Jones A. (2015). Protection and care needs in later life. Presentation to the Institute and Faculty of Actuaries.

Law Commission (2014). Data sharing between public bodies. A scoping report. http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc351_data-sharing.pdf

London Councils. Accessing care in 2016 and beyond: A step-by-step guide for over 65s. https://www.londoncouncils.gov.uk/node/25653

London Councils. The Care Act 2014. The most significant changes in adult social care since 1948 to be implemented from April 2015 and April 2016. http://www.londoncouncils.gov.uk/our-key-themes/health-and-adult-services/adult-social-care/care-act-2014.

Lord Prior of Brampton. (2015). Cap on care costs: Written statement – HLWS135. http://www.parliament.uk/business/publications/written-questions-answers-statements/written-statement/Lords/2015-07-17/HLWS135/..

Mental Health Act 1983. London, The Stationary Office. http://www.legislation.gov.uk/ukpga/1983/20/contents

NHS Trusts and Primary Care Trusts (Sexually Transmitted Diseases) Directions 2000. Department of Health. http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsLegislation/DH_4083027

Nuffield Trust with PSSRU at the London School of Economics (LSE) (2012). Care for older people – Projected expenditure to 2022 on social care and continuing health care for England's older population.

Office for National Statistics. http://www.ons.gov.uk/ons/index.html

Reform of the data protection legal framework. Update 23/10/2014. http://ec.europa.eu/justice/data-protection/review/index_en.htm Accessed 09/06/2015.

Rolfson DB, Majumdar SR, Tsuyuki RT, Tahir A, Rockwood K. (2006). Validity and reliability of the Edmonton Frail Scale. Age Ageing 35 (5): 526-529. doi: 10.1093/ageing/afl041.

Rubin L. et al. (2014). An overview of the US LTC insurance market (Past and present): The economic need for LTC insurance, the history of LTC regulation & taxation and the development of LTC product design features. Managing the impact of Long-term care needs and expense on retirement security monograph. Society of Actuaries.

https://www.soa.org/Library/Monographs/Retirement-Systems/managing-impact-ltc/2014/mono-2014-managing-ltc.aspx

Rubin L. et al. (2014). An overview of the US LTC insurance market (Past and present): The economic need for LTC insurance, the history of LTC regulation & taxation and the development of LTC product design features. Managing the impact of Long-term care needs and expense on retirement security monograph. Society of Actuaries. https://www.soa.org/Library/Monographs/Retirement-Systems/managing-impact-ltc/2014/mono-2014-ltc-manage-narva.pdf

Shelter (2012). A better fit? Creating housing choices for an ageing population. http://england.shelter.org.uk/professional_resources/policy_and_research/policy_library/policy_library_folder/a_better_fit_creating_housing_choices_for_an_ageing_population

Statistics and Registration Act 2007. Chapter 18. London: The Stationary Office. http://www.legislation.gov.uk/ukpga/2007/18/pdfs/ukpga_20070018_en.pdf Accessed

Stone E. (2011). What does the Dilnot report propose? http://www.jrf.org.uk/blog/2011/07/what-does-dilnot-report-propose

Towers Watson (2015) De-risking report 2015. The evolving bulk annuity and longevity swap market. https://www.towerswatson.com/en-GB/Insights/IC-Types/Survey-Research-Results/2015/03/De-risking-report-2015

Turner A, Drake J, Hills J. A New Pension Settlement for the Twenty-First Century. The Second Report of the Pensions Commission. Pensions Commission; 2005. http://www.webarchive.org.uk/wayback/archive/20070802120000/http://www.pensionscommission.org.uk/publications/2005/annrep/annrep-index.html

UK Statistics Authority. (2009). Code of practice for official statistics. Edition 1.0. Jan 2009. Crown Copyright. http://www.statisticsauthority.gov.uk/assessment/code-of-practice/

UK Statistics Authority. (2014). Better statistics, better decisions. Strategy for UK statistics, 2015 to 2020. http://www.statisticsauthority.gov.uk/news/strategy-for-statistics-2015-to-2020.pdf

Wanless D. (2002). Securing our future health: taking a long-term view. HM Treasury, 2002. http://webarchive.nationalarchives.gov.uk/+/http:/www.hm-treasury.gov.uk/consult_wanless_index.htm

Ward M, Afkami R. UK Data Service. (2013). How to set up and run a Data Service. http://data-archive.ac.uk/media/417728/htr_accessnov2013.pdf

Wood C, Demos. (2013). The top of the ladder. http://www.demos.co.uk/files/TopoftheLadder-web.pdf?1378922386

Section 7. Glossary

Activities of Daily Living (ADL)	A measure of independent living, the ability to undertake basic tasks such as washing, dressing, and getting in/out of bed.
Annuity	A fixed sum of money paid to someone each year, typically for the rest of their life.
Anonymised data	Data from individuals that do not contain any details that would allow anyone to identify the individual.
Biobank database	A repository of anonymised data from 500,000 volunteers in the UK initially aged between 40 and 69 years, where data are available to bona fide health-related researchers.
Bonds	An investment where money is lent to a corporate or governmental body for a defined period of time, at a fixed or variable interest rate.
Bulk annuity	A single annuity policy supplied by a PRA authorised insurance company to pay pensions for a group of people, typically members of the same pension scheme. The premium is usually paid as a lump sum at outset but can be spread or deferred.
Clinical Practice Research Datalink (CPRD)	A repository of primary care health records in the UK, where data access by the private sector is restricted.
Defined benefits pension	A scheme where the pensioner is guaranteed a pension that matches a defined proportion of their pre-retirement salary.
Defined contributions pension	A scheme where the individual contributes a specific proportion of their salary into a pension pot, but the size of the pension cannot be predicted.
Aged dependency ratio	The ratio of people of working age in the population to those who are retired, which has been historically estimated as the ratio of those between the ages of 15 and 64 to those aged 65 years and over.
Enhanced or impaired annuities	Use an invested pension pot to provide an income for life, based on health circumstances of individuals with pre-existing disease that may impair their life expectancy.
Equity release schemes	Loans that use the equity in property, usually the family home, as collateral against the loan.
Extra care schemes	Also known as “very sheltered housing”, a form of specialist housing where the occupant owns the property, which has access to additional domestic and personal care support and social facilities.
Final salary pension	Another term for defined benefits pension, where the pensioner is guaranteed a pension that matches a defined proportion of their pre-retirement salary.
Fixed annuities	Use an invested pension pot to provide a guaranteed fixed income for life.
General needs housing	Standard housing stock suitable for the general population that has no special provision for any particular segment of society such as the elderly.
Health and care risk	The risk that poor health will result in care bills, which will diminish any accumulated retirement assets.
Health and Social Care Information Centre, HSCIC	The national provider of information, data and IT systems for health and social care in England.
Health Survey for	An annual survey of the health of individuals in England,

England	overseen by the Health and Social Care Information Centre, where access to individual data by the private sector is restricted.
Home reversion schemes	A property owner raises income from selling all or a share of the property, but is allowed to live in the property until their death or move to residential care.
Inflation risk	The risk that the rising cost of living will erode the buying power of retirement assets.
Interest rate risk	The risk that the current levels of interest will adversely affect the amount of income to be received from the retirement savings.
Individual Savings Account (ISA)	A savings scheme where individuals can hold cash, shares and unit trusts free of tax on dividends, interest and capital gains.
Instrumental Activities of Daily Living (IADL)	A measure of independent living, the ability to undertake basic tasks such as using the phone.
Lifetime mortgage	A type of reverse mortgage, where the policyholder retains ownership of the property against which a loan is raised. The loan is paid off when the policyholder dies or the house is sold.
Longevity hedge	A scheme that makes an agreed schedule of payments to a counterparty based on an 'expected' mortality assumption in respect of a specified group of members. In return, the scheme receives actual payments, which are linked to whether the scheme members underlying the hedge are alive or not at each payment date. The longevity risk for this group of members passes from the scheme to the hedge counterparty.
Longevity risk	The risk that the individual will outlive the total income that can be received from their retirement assets.
Market risk	The risk that throughout the savings period the investment returns on retirement assets will have been poor.
Metadata	Data that describe or summarise other data.
Pension pot	A measure of the accumulated savings an individual has invested in their pension scheme at the time of his or her retirement.
Personal data	Data that relate to a living individual who can be identified from those data; or from other information about an individual that is held in confidence by an organisation.
Public good	A commodity or service that is provided without profit to all members of society.
Retirement assets or savings	A measure of the total accumulated savings an individual has at the time of his or her retirement.
Retirement savings products	A product where premiums from the policyholder are invested by a financial institution and the savings accumulate after removing an administration fee.
Retirement village	A community of specialist housing for older adults.
Risk factors	Any item of data that can affect the health or life expectancy of an individual.
Regression modelling	A mathematical modelling method that determines how far the variation in one factor is affected by changes in one or more other factors.
Savings risk	The risk of having insufficient accumulated savings in the retirement assets to fund the whole retirement.

Sheltered housing	A form of specialist housing for older adults.
Specialist housing	Housing exclusive to people of older ages, which typically includes care and support services and other communal facilities.
Variable annuities	Use an invested pension pot to provide an income for life, increasing at level of inflation, or a fixed rate.

Appendix. Key legislation

A.1. Statistics and Registration Service Act 2007 (c.18)

What is the Act?

Primarily concerned with the structure of the organisations that will deliver the statistics and registration services in future.

Creates an independent Statistics Board (**UK Statistics Authority**) as a Non-Ministerial Department (NMD) accountable to Parliament.

Objectives are to promote and safeguard:

- The production and publication of official statistics that serve the **public good**; and
- the quality, good practice and comprehensiveness of official statistics.

Board functions include:

- monitoring/reporting of all official statistics, whether or not they are National Statistics;
- conducting independent assessment (for quality/integrity) of key statistics produced by the Office for National Statistics (ONS) and other departments for formal approval as National Statistics;
- developing and publishing a Code of Practice to assess statistics (Section 2: Code of Practice for Official Statistics); and
- having oversight of the ONS, replacing the role which Treasury Ministers previously performed.

Board membership:
Non-Executive positions include the Chair and at least 5 other members.

Executive positions include the National Statistician (Chief Executive and Chief Statistical Advisor) and Head of Assessment (principal advisor on Assessment of statistics).

Includes the devolved administrations of Scotland, Wales and NI.

What does it do?

The Act incorporated a number of changes:

- The new organisation replaces Statistics Commission and ONS.
- The Board replaces Ministers as the top layer of governance for the ONS.
- The ONS will become the Board's Executive Office, managed by the National Statistician who will be the Board's Chief Executive and who will report to the Board rather than to Ministers.
- The Board will develop and publish a new **Code of Practice** against which all of ONS's products, and all of the 'National Statistics' released by other Government Departments, will be assessed for compliance.
- The Act allows for increased sharing of data between ONS and other Departments, subject to agreement by Parliament on a case-by-case basis. At the same time **the Act outlines measures designed to protect the confidentiality of personal information**. Anyone guilty of contravening the Act will be liable for a fine, a prison sentence of up to two years, or both.

A number of points remained unchanged:

- Legislation does not alter the basic structure for statistical production in the UK. The ONS, as an integral part of the new Statistics Authority, will retain its position as the UK's National Statistics Institute (NSI), and the devolved administrations and policy departments will retain responsibility for all those statistical outputs which cover their own areas of responsibility.

What's new in this?

The Act introduced key structures and concepts including:

- The new Statistics Authority, a non-ministerial department acting at arm's length from Ministers. The Authority **has statutory responsibility to promote and safeguard production and publication of official statistics that serve the public good**.[78]
- The role of National Statistician.
- The concept of National Statistics.
- The Code of Practice for Official Statistics.
- The Independent Statistics Commission.

A.2. Code of Practice for Official Statistics.

The Code of Practice for Official Statistics recognises that the dissemination of official statistics should meet the requirements of informed decision-making by various stakeholders including business. Relevant aspects of the Code include the following:

Identifying business as a part of the stakeholder community

- **Principle 1: Meeting user needs.** The production, management and **dissemination** of official statistics should meet the requirements of informed decision-making by government, public services, **business**, researchers and the public.
- Principle 1, Practice 2. There is a requirement to investigate and **document the needs of users** of official statistics, the use made of existing statistics and the types of decision they inform.

Establishing public interest

- **Principle 3: Integrity.** At all stages in the production, management and **dissemination** of official statistics, the **public interest should prevail** over organisational, political or personal interests.
- Practice 4: All **statutory obligations and internationally endorsed guidelines governing the collection of data, confidentiality and release** must be followed.

Ensuring data security and confidentiality

- **Principle 5: Confidentiality.** Private information about individual persons, including bodies corporate, compiled in the production of official statistics is confidential, and should be used for statistical purposes only.
- Principle 5, Practice 1: **Ensure that official statistics do not reveal the identity of an individual** or organisation, or any private information relating to them, taking into account other relevant sources of information.

---

[78] Statistics and Registration Service Act 2007. Section 7(1) Objective: "In the exercise of its functions under sections 8 to 21 the Board is to have the objective of promoting and safeguarding the production and publication of official statistics that serve the public good".

- Principle 5, Practice 4: Ensure that **arrangements for confidentiality protection are sufficient to protect the privacy of individual information**, but not so restrictive as to limit unduly the practical utility of official statistics. Publish details of such arrangements.
- Principle 5, Practice 6: In every case where confidential statistical records are exchanged for statistical purposes with a third party, **prepare written confidentiality protection agreements** covering the requirements under this Code. **Keep an operational record** to detail the manner and purpose of the processing.

Ensuring user engagement and maximum public value

- **Protocol 1: User engagement.** Effective user engagement is fundamental both to trust in statistics and **securing maximum public value**. This Protocol draws together the relevant practices set out elsewhere in the Code and expands on the requirements in relation to consultation.
- Protocol 6, Practice 6: **Seek feedback from users** on their experiences of the statistical service they receive, data quality, and the format and timing of outputs. Review the feedback systematically.

A.3. Better Statistics, Better Decisions: Strategy for UK Statistics 2015-2020

The current 5 year strategy (2015-20) documented in this report reiterates the "*statutory objective of promoting and safeguarding the production and publication of official statistics that serve the public good*".[79] Relevant sections include the following:

Mission Statement

- **"***Official statistics are for the **benefit of society and the economy** generally. They allow the formulation of better public policy and the effective measurement of those policies; they inform the direction of economic and commercial activities …*". (p.4)

New opportunities with data (p.5)

- "*The growing data capability in other organisations presents us with new opportunities to collaborate. We must retain and develop the skills that are core to our business, while adopting creative solutions … such as outsourcing and **developing partnerships across the private and public sectors***".

Objective 1: Inform decision making (p.7)

- "*We will provide a firm evidence base for sound decisions … and **informing the direction of economic and commercial activities***".

- **"***We will champion the public interest, making sure that **key data used for decision-making are available to all**, subject to the protection of confidential personal data*".

Objective 3: Improve communication (p.7)

---

[79] UK Statistics Authority (2014). Foreword.

- **"***We will work closely with the Government Digital Service to build on work already underway to embed the principles of* ***open data and digital by default*** *to official statistics …* ".

Objective 6: Develop and implement innovative methods (p.9)

- *"We will achieve a step-change in the sharing of data within, and beyond, government for statistical purposes, working across government to overcome legal and bureaucratic challenges. This presents an opportunity for radical benefits for public policy decisions. We will facilitate greater use and linkage of administrative data via the Administrative Data Research Network".*

A.4. Health and Social Care Act 2012

What is the Act?

The Act contains 12 Parts and 23 Schedules addressing a range of issues relating to health and social care. The Act makes changes to a number of existing Acts, most notably the National Health Service Act 2006 ('the NHS Act').

The Act gives effect to the policies that were set out in the White Paper *Equity and Excellence: Liberating the NHS,* which was published in July 2010.

The main aims of the Act are to change how NHS care is commissioned through the greater involvement of clinicians and a new NHS Commissioning Board; to improve accountability and patient voice; to give NHS providers new freedoms to improve quality of care; and to establish a provider regulator to promote economic, efficient and effective provision. In addition, the Act will underpin the creation of Public Health England (PHE), and take forward measures to reform health public bodies.

What's new in this?

The Act sets out provisions in Part 9 for information standards and data collections. As a result:

- **Information standards now have a legal status,**[80] with NHS England (NHS Commissioning Board) and the Secretary of State empowered to publish an information standard.[81]

- Increased powers have been given to the **Health and Social Care Information Centre (HSCIC)** to establish information systems for the collection or analysis of information:

  "*The Health and Social Care Act 2012 includes provisions marking a step-change in the health and social care sector's approach to transparency, growth and open data. It requires the HSCIC to publish (in 'safe, de-identifiable format') virtually all data that it is required to collect across the health and care sector*".[82]

---

[80] Section 250 enables the Secretary of State/NHS Commissioning Board to set information standards for health services or adult social care in England.

[81] Targeted towards providers, commissioners of publicly funded health and social care services.

[82] Department of Health. The power of information: Putting all of us in control of the health and care information we need. p. 99.

The HSCIC is to maintain and publish a register or catalogue of the data it has collected and undertake work to develop an inventory of the 'wealth of data' collected by other parts of the health and social care system.[83]

What is the result?

The Act enables the HSCIC to:

- act as national focal point and key resource for health (NHS, PHE) and social care information;[84]
- publish, with exceptions, the information it collects; and
- hold and link confidential data from individual health and care records. However, information made will be aggregated and anonymised before being made public.[85]

Health and Social Care Information Centre

The Health and Social Care Information Centre (HSCIC) was established (1 April 2013) by the Health and Social Care Act 2012 as an executive agency of the Department of Health.

Core Functions include the following:

- Operation of the key data and information systems in support of the NHS, social care services and the wider health and social care sector.
- Development of the next generation of national data and information systems.
- Analysis, publication and dissemination of data and information to enable professionals, commissioners, regulators, researchers and especially individual citizens to understand the safety and effectiveness of care services and make informed decisions about personal, individual and community-wide health and social care.

Statutory Duties include the following:

- The collection, storage and analysis of national healthcare, public health and social care data, including personal confidential data.
- Acting as the custodian or guardian of National and Official Statistics for health, public health and social care.
- Assessing and assuring the quality of the data they collect.
- Designing, delivering and managing any programme or technical service for the health and care system, as directed by the Secretary of State for Health or NHS England (NHSE).
- Establishing and operating systems for the collection or analysis of information as directed by the Secretary of State for Health or NHSE.
- Publishing a code of practice for the collection, analysis, publication and other dissemination of confidential information concerning, or connected with, the provision of health services or of adult social care in England.

---

[83] Most national data collected for social care are made available from the Information Centre.

[84] Most data collected nationally for Social Care are made available from HSCIC.

[85] Routine data release (statistical publication) was initiated in 2011-12. An additional 83 data sets were released for the first time during this period.

- Publishing a register of the collections and the contents of each collection that they manage.
- Establishing and publishing a database of quality indicators in relation to the provision of health services and adult social care in England.
- Assessing the extent to which information collected meets the information standards, so far as they are applicable, and publishing a record of the results of the assessment.
- Working with other national bodies to deliver a year-on-year reduction in administrative burden on the front line.

HSCIC as 'guardian of data' and primary contact point

"*Since the end of the year the governance responsibilities of the HSCIC have been expanded to provide system wide advice on operational information governance across the health and social care sectors. This is separate from its principal role of guardian of data which is set out in the Health and Social Care Act 2012. The HSCIC will host the Information Governance Alliance which will act as the primary point of contact for advice and guidance to the wider system. HSCIC will also deliver a programme of assurance across the health sector as directed by the Secretary of State, to determine where enhancements or additional capabilities at a local, regional and national level can be made*".[86]

A.5. Code of practice on confidential information HSCIC 2014

The Code builds upon Dame Fiona Caldicott's Information Governance Review document '*To share or not to share?*[87]. Of note is Caldicott Principle 7: "*The duty to share information can be as important as the duty to protect patient confidentiality*".

The Code is targeted towards:

- health/social care bodies which collect, analyse and publish or otherwise disseminate **confidential information** in relation to the provision of health/adult social care (England); and
- persons other than public bodies who provide health/adult social care as a part of an arrangement with a public provider.

Confidential information is defined as:[88]

- "*Information which is in a form which identifies any individual to whom the information relates or enables the identity of such an individual to be ascertained".*
- *"Any other information in respect of which the person who holds it owes and obligation of confidence*".

The Code specifies the HSCIC can only disseminate confidential information where "*the intended purpose is in connection with the provision of health care or adult social care, or the promotion of health*".[89] It **prohibits dissemination "*for solely***

---

[86] Williams, A. Health and Social Care Information Centre Annual Report and Accounts 2013/14. p.47.

[87] Caldicott (2013).

[88] Code of Practice on Confidential Information. HSCIC. December 2014. p. 8.

[89] Ibid p. 11.

commercial intended purposes such as for commercial insurance".[90]

The Code draws its legal basis from the following:

- Sections of the Health and Social Care Act 2012.[91]
- s92 of the Care Act 2014.
- Code of Practice for Official Statistics 2009.Data Protection Act 1998: i. Schedule 1, Part 1, Principle 2 and common law duty of confidence; ii. Schedule 1, Part 1, Principle 5.

---

[90] Ibid p. 11.

[91] s254, s259, s260(2), s260(3), s263(1), s263(2), s263(5), s263(7), s264, s265(1) – s265(3), s265(5), s274(9).

Disclaimer

The opinions expressed in this publication are those of the authors. The material is for general information only and does not constitute investment, tax, legal or any other form of advice. You should not rely on this information to make (or refrain from making) any decisions. You should always obtain independent, professional advice for your own particular situation. The authors offer no guarantee for the completeness or veracity of the contents of this publication. The statements in this publication may provide expectations of past, current and future events based upon certain assumptions. These statements involve known and unknown risks, uncertainties and other factors which are not exhaustive. The authors of this publication undertake no obligation to publicly revise or update any statements, whether as a result of new information, future events or otherwise. To the fullest extent permitted by law, neither the authors nor their affiliates shall be liable for any direct or consequential loss occasioned to any person acting, omitting to act or refraining from acting in reliance upon the information detailed in this publication. Consequential loss means any loss of anticipated profits, damage, expenses payable to any third party or any other indirect losses.