Using case finding and risk stratification:

A key service component for personalised care and support planning

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NHS England Equality Statement

"Equality and diversity are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have given due regard to the need to:
- *Reduce health inequalities in access and outcomes of healthcare services integrate services where this might reduce health inequalities*
- *Eliminate discrimination, harassment and victimisation*
- *Advance equality of opportunity and foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it."*

Contents

Foreword for Using Case Finding & Risk Stratification

This handbook describes current thinking and provides practitioner insights into case finding and risk stratification to support personalised care and support planning – both of which are key elements of the vision and outcomes in the NHS Five Year Forward View[1] .

The handbook contains latest advice on issues such as fair processing of data and Information Governance (IG), as well as linking to practical guidance, case studies and theory from organisations who are closely involved in this area. The purpose of this handbook is to share the learning from these organisations more widely. The handbook also acts as a resource to sign-post the diverse published literature on risk stratification and case finding.

Case finding and risk stratification are evolving disciplines and as legislative changes are expected for Information Governance and use of data during 2015, we would like to emphasise that this resource is the first step of an on-going dialogue with a field of experts, some from the Year of Care and Integrated Care Pioneer programmes. We intend to draw on collective experience and help to move others to a similar level of understanding, We acknowledge there is more to learn in the future as case finding and risk stratification are sufficiently complex to comprise a significant challenge to widespread implementation. A very useful and specific discussion paper on risk stratification in the NHS is included at Section 3.

Nevertheless, we hope the handbook will be useful in supporting use of case finding and risk stratification as tools or approaches for local business planning and care planning, particularly in relation to populations with multi-morbidity and complex conditions.

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[1] *Five year forward view,* http://www.england.nhs.uk/ourwork/futurenhs/

1. Introduction

1.1 The three handbooks

1.1.1 Background

This resource forms part of a set of three 'how to' handbooks . It is designed for commissioners and commissioning support organisations, GP practices and community health and social care staff involved in the challenge of planning and delivering person-centred care for their populations, thus improving services for people who are living with long term conditions and/or frailty.

1.1.2 How were the handbooks produced?

These resources were produced by a Task Group of service leads from Clinical Commissioning Groups (CCGs), GP practices and other stakeholder organisations, supported by NHS England. They contribute to the work of the 'Long term conditions, older people and end of life care' programme.

The resources are intended as practical support on *how* to meet the challenge of providing person-centred care through arguably, the three most important service components:

- **Case finding and risk stratification** *– how to segment a population and provide person-centred care to those most in need, recognising resource constraints;*
- **Multi-disciplinary team working** - *how health and care professionals work together to support people with complex care needs that have been identified through case finding and risk stratification;*
- **Personalised care and support planning** *– the key vehicle by which health and care professionals work together with patients and carers to meet their individual care needs.*

The components complement each other and are all key to successful care planning and integration. They can be accessed and downloaded through the Domain 2 main web page for improving the quality of care for people with long term conditions, on the NHS England website.

Information about other components that contribute to care planning can be found in the House of Care toolkit and resources at http://www.england.nhs.uk/house-of-care/

The **National Voices** programme of work[2] produced a generic narrative in May 2013 and this included a definition of person centred, co-ordinated care

"My care is planned with people who
work together to understand me and my carer(s),
put me in control, co-ordinate and deliver services to
achieve my best outcomes"

1.1.3 Why are the resources needed?

Frontline organisations have requested greater clarity on what good clinical integration actually means and how it can be achieved in practice. The resources are intended to be practical, pragmatic and evidence based where possible. They should contribute to business planning toolkits for 2015/16 and beyond, including delivery of elements of the enhanced service for unplanned admissions.

They are not the final word on these evolving areas but are intended to provide time-pressed commissioners and practitioners with a 'handbook' that brings together in a single place snapshots of best practice examples, practical lessons and the latest academic research.

1.1.4 Who are they for?

Each of the three resources is intended for use by:

- commissioners to purchase and promote services that demonstrate good clinical integration and allows for local variation;
- health and care professionals to develop clinically integrated services that put patients' needs at the fore.

In producing the handbooks, we have been conscious that a balance is needed between defining them at a sufficiently high level to allow local flexibility, and providing enough detail to be meaningful to clinicians and other professionals.

Co-producing resources with clinicians, CCGs and other stakeholders is vital to ensure they develop in a consensual and considered way that is useful in practice across various contexts. The exact form for each of the handbooks has been based on what might be most useful in practice, so the content for each is different.

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[2] For more information about National Voices, see http://www.nationalvoices.org.uk/defining-integrated-care

2. Background for Case finding and Risk stratification

2.1 Definitions

2.1.1 Case finding and risk stratification are similar concepts but they have distinct definitions and objectives:

- **Case finding** is a systematic or opportunistic process that identifies individuals (e.g. people with COPD) from a larger population for a specific purpose for example, 'Flu vaccination

- **Risk stratification** is a systematic process that can be used for commissioning as it divides a population into different strata of risk for a specified outcome, e.g. unscheduled admission to hospital

- These concepts combine in **risk stratification for case finding,** which is a systematic process to identify sectors of the population that may benefit from additional clinical intervention, as directed by a lead clinician such as the patient's GP. This third definition describes the current risk stratification (for case finding) programmes enabled by Confidentiality Advisory Group (CAG) application CAG 7-04(a)/2013[3].

All three concepts are increasingly important processes that are essential to core stated objectives in the NHS England Business Plan: to involve people with long term conditions (LTCs); to deliver wider primary care at scale; and to provide modern integrated services.

There are pockets of considerable existing experience and our aim is for this to deepen and spread. In particular, primary care teams should be encouraged to become much more closely involved. This is because some available risk stratification and case finding tools can be relatively crude and require practitioner involvement for effectiveness.

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[3] The full title of the application is: *Disclosure of commissioning data sets and GP data for risk stratification purposes to data processors working on behalf of GPs (CAG 7-04(a)/2013).* Details of the application's status and minutes of the relevant committees can be found at: http://www.hra.nhs.uk/about-the-hra/our-committees/section-251/cag-advice-and-approval-decisions/

2.1.2 Current challenges posed by Information Governance (IG)

The use of patient data for risk stratification and case finding raises a number of distinct challenges. It is crucial that these are considered and planned for at the earliest stage of any programme. They are:

- Being clear on the purpose(s) for the use of information and ensuring a lawful basis is identified that take account of the Data Protection Act 1998, the Common Law Duty of Confidentiality and the Human Rights Act 1998;
- Ensuring the correct contracts and agreements are in place between each party. These need to clearly articulates the roles and responsibilities of data controllers and data processors;
- Outlining how information will flow and how it will be managed, covering, for example, issues such as patient objection management

The following are key early indicators for the success of any programme:

- The approach is patient focused, starting with the direct care needs of the patient and working outwards;
- Clinicians are involved at the early stage and throughout the process, and supported in their role as gatekeepers for patient participation;
- Communication with patients, and managing choice, is built into the design of the programme.

The current Section 251 approved   Risk Stratification (CAG 7-04(a)/2013) is scheduled to conclude in April 2015. This application specifically covers the use of commissioning data sets and GP data for the purpose of risk stratification. The planning, procuring and design of your programme will need to account for this.

Advice note: for the foreseeable future, programmes must maintain a watching brief on the legal context around case finding and risk stratification in order to ensure any changes are managed.

The experience of successful risk stratification (for case finding) programmes has shown that early and ongoing clinical involvement is key to better outcomes for patients. Primary care teams have told us that they would like much greater reassurance about risk stratification for case finding.

2.1.3 A data-led but clinically informed process

It has become clear that, in general terms, populations and individuals with increasing numbers of LTCs and frailty experience greater risk of adverse outcomes. What is less clear is whether particular LTCs, either individually or in combinations, should be the focus of attention.

The current fragmentation of our health and social care services is reflected in the diversity of national and local data systems. The technical aspects of interoperability and the legal aspects of data sharing continue to inhibit the full potential of risk stratification and case finding. The ambition for the future is to be able to share primary care, community health, mental health, secondary care, social care and ambulance service data in a secure, whole system approach.

There are several general approaches to risk stratification and case finding. No single one is ideal as each has advantages and disadvantages.

2.2 Uses for Case Finding & Risk Stratification

2.2.1 Clinical uses (or uses that relate to, or enable direct care)
- to identify people with highly complex, multiple morbidity and/or frailty (and their carers), who might benefit from multi-disciplinary team support as part of case management and care planning;
- to identify and target specific service needs of patient groups, (e.g. for people with diabetes in order to improve their quality of care, experience of care and clinical outcomes);
- to identify suitable patients for the caseload of specialist nursing or medical services such as community geriatricians, community matrons or mental health practitioners for example, or for end of life advance care planning, use of the Electronic Palliative Care Co-ordination System (EPaCCS); or to reduce unnecessary unplanned admissions.

2.2.2 Uses other than direct care might be:
- planning work for commissioning services and contracts;
- for setting up capitated budgets;
- to inform Better Care Fund distribution for people with multiple LTCs.
- where it is possible to add in certain **social care data** into a risk engine, case finding and risk stratification can support an approach which aims to identify the health AND social care determinants of risk of admission to hospital, or other adverse social care outcomes. In certain cases this might be, for example, permanent admission to a care home.

Advice note: in each of these instances a clear, lawful basis for the use of personal confidential data needs to be identified. Although the inclusion of social care data is challenging in the current legal context, options such as seeking explicit consent are available.

2.2.3 The following model illustrates how a population might be segmented for case finding. However, the *shape and size* of the sections might look different if the model is used to show future service utilisation as there are far more people in the second segment (17% - 20%).
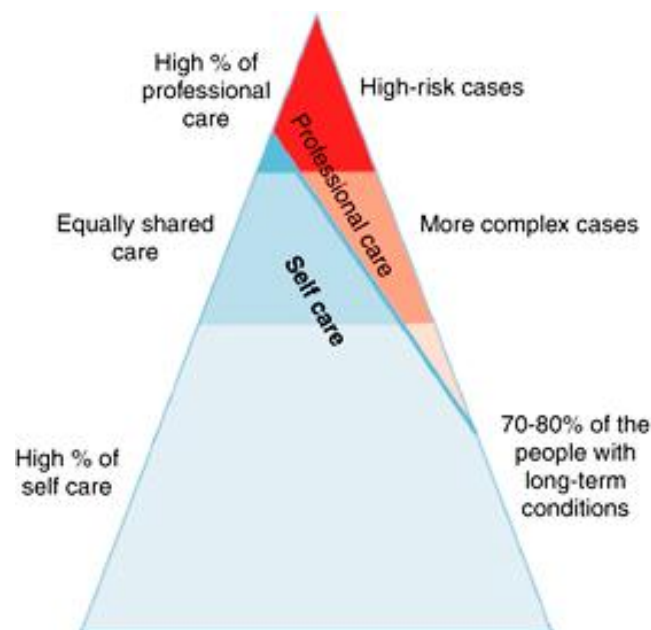
The paper by Martin Roland and Gary Abel [4] is a useful reference on segmentation, see http://www.bmj.com/content/345/bmj.e6017

Case finding is explored in more detail in **Section 3.**

2.2.4 Uses for risk stratification include:
- identifying segments of a population at higher risk of experiencing a particular outcome (such as unplanned/emergency admission) on the basis of recent intensive health care use and/or the presence of LTCs – that is, predicting the future on the basis of the recent past;
- stratifying populations based on: disease profiles; conditions currently being treated; current service use; pharmacy use and risk of future overall cost.

All these functions would support commissioning as well case finding activities.

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[4] 'Reducing emergency admissions: are we on the right track?'   *BMJ* 2012; 345:e6017

Advice note: as before, each use requires a clear, lawful basis for identifying personal, confidential data. The distinction between case finding and commissioning is sufficiently large to require a clear lawful basis for each purpose.

2.2.5 Including people with frailty in risk stratification and case finding

As approximately one third of older people with frailty have only one LTC, or none at all[5], these people can remain invisible within the operating parameters of risk stratification tools based on LTCs. Also older people with this condition typically use health resources most intensively during the last year of life. This implies a **late diagnosis** in the trajectory of frailty when preventative interventions may be **ineffective.**

There are several simple, quick and well validated tools that have been developed to identify people with frailty. They have been reviewed in the British Geriatrics Society report '*Fit for Frailty*' .http://www.bgs.org.uk/index.php/press/2954-fff-media

2.2.6 Although set piece tools comprise an important, but not exclusive, mechanism to facilitate case finding, local intelligence gathering has a role in augmenting the information and in supporting the case finding approach. Increasingly, people will self-identify as being at risk (e.g. using the walking speed test to self-identify frailty). Use of emergency alarms, ambulance call outs, A&E attendances and social care requests are all examples of valuable information and intelligence that will contribute to a population based understanding of at risk people.

2.2.7 Three frailty codes have been made available by the Health and Social Care Information Centre (HSCIC): mild; moderate and severe frailty. This will facilitate frailty registers to be established in primary care in a similar way to a LTC.

2.2.8 Three easy to apply examples of screening tools for frailty are included here:

    a) The Walking Speed Test;

    b) The PRISMA 7 Questionnaire;

    c) The electronic Frailty Index

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[5] Fried L, Tangen C, Walston J, Newman A, Hirsch C, Gottdiener J, et al. Frailty in Older Adults: Evidence for a Phenotype. Journal of Gerontology: Medical Sciences 2001;56A(3):M146-56.

The accuracy of the various tools available for earlier detection of frailty is compared in the table below:

Diagnostic Test Accuracy (DTA) for simple frailty instruments (Systematic Review)

	Sensitivity	Specificity
Gait Speed <0.8m/s	99%	64%
PRISMA 7	83%	83% (wide CIs)
Self-reported Health	83%	72% (wide CIs)
Polypharmacy (>5 meds)	67%	72%
GP clinical assessment	58%	72%

(Frailty instruments assessed against a reference standard)

2.2.9 A CQUIN for identifying frailty (NHS Kernow, Cornwall)

Community Services in areas of Cornwall are implementing a CQUIN to promote identifying and recognising frailty.

The template they are using can be accessed here.

3. General advice about risk stratification

3.3.1 Current situation

During 2005 to 2007, the Department of Health commissioned the King's Fund to produce software and predictive tools to identify people who were at high risk of re-admission to hospital. This led to the development of the PARR++ and Combined Predictive Model tools. The Department has not funded updates since 2011 and so unless recalibrated, these tools are potentially compromised as they rely on previous HRG codes.

Since 2011, a number of products have been developed by commercial or academic providers with the result that the use of risk stratification databases and tools within the NHS has dramatically increased over the past few years. The tools are a means of identifying high risk individuals who may benefit from case management as well as for identifying patient groups or populations at higher risk of unplanned urgent admissions, who might benefit from a suite of population based interventions. Interventions might be of a general, public health type or disease specific programmes such self-management education in diabetes. Based on the list of approved risk stratification providers (November 2014) it is likely that they are being used by around half of the 211 CCGs across England. The list also provides information about when certification/approval was provided.

The list of risk stratification suppliers in the assurance statement are those that are approved to use the Section 251 application (CAG 7-04(a)/2013). The list is not a list of "approved" risk stratification suppliers in all circumstances but **within the particular context of the application**. Where organisations can identify an alternative **legal basis**, they are not required to use this Section 251, nor are they restricted to suppliers detailed on the list. In addition, readers are reminded that the application CAG 7-04(a)/2013 is **due to expire in April 2015**.

3.3.2 Evidence base and practicalities to consider

York University have carried out a rapid synthesis and review of evidence to assess the predictive ability of tools used to identify people living with multiple long-term chronic health conditions, who are at risk of future unplanned hospital admissions. It is important to note that while the majority of such patients will be older, significant numbers of people under 65 live with one or more long term condition. In areas of higher socio-economic deprivation, this number will be higher than the England average for any given age group.[6]

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[6] The Clinical Effectiveness Group, Queen Mary Hospital for London, are working with Tower Hamlets CCG on proposals for a fairer formula for national funding allocations to GP practices. The formula would be based on life expectancy at birth rather than chronological age, which is used for the minimum practice income guarantee

York University identified seven studies evaluating sixteen risk screening tools used in commissioning or in primary care settings in the UK or equivalent health systems. Overall, the rapid review found that the models identified were reasonably similar in terms of their predictive performance (based on reported c-statistics). However, the underlying populations, data sources and coding differed, so this finding can only be considered as indicative and should not be regarded as a definitive estimate of comparative performance. Given this, the review does not recommend any specific tool over another. One consideration might be to check requisition and revenue costs as some tools are expensive. The rapid review is available at http://www.york.ac.uk/inst/crd/pdf/predicting%20unplanned%20admissions.pdf

3.3.3 Risk stratification is a topic of intense research, and as stated in the Foreword, this handbook is not the last word on the subject. An NHS England discussion paper on potential next steps for risk stratification in the NHS is available here.

3.3.4 Choosing risk stratification tools: what to look out for

NHS England made an application under Regulations enabled by Section 251 of the NHS Act 2006 for GP led, CCG co-ordinated, risk stratification programmes.[7] This application, CAG 7-04(a)/2013, is specifically for the use of commissioning data sets and GP data sets. Within the application are a number of suppliers who are "approved" to use this lawful basis for the specified purpose and within the conditions of approval. However, this is not a definitive list of risk stratification tools and is not a list of those tools "approved" by NHS England.

Each risk stratification programme must consider which option is best for them and account for the potential changes to legal context that may occur. Programmes should seek to evaluate the effectiveness of the risk stratification tools under-consideration. Key to the evaluation is compliance with the privacy impact assessment, a process which plays a crucial role in asking the right questions about the use of patient data at the start of any programme.

NHS England's recent guidance, 'Proactive care programme: CCG support for implementation' (May 2014) in relation to the enhanced service payment for avoiding unplanned admissions has a useful checklist on choice of risk stratification tools at Annex A of the document. See http://www.england.nhs.uk/wp-content/uploads/2014/06/avoid-unpln-admss-ccg-guid.pdf

Also useful as a general overview is the document *'Choosing a predictive risk model: a guide for commissioners in England'* which was published by the Nuffield Trust in

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[7] The relevant regulation can be found at http://www.legislation.gov.uk/uksi/2002/1438/contents/made and the relevant section of the National Health Service Act 2006 can be found at: http://www.legislation.gov.uk/ukpga/2006/41/section/251

2011.[8] This was intended to help commissioners select a predictive model from the many tools available at the time. The report highlights a range of factors to consider, including whether to 'make or buy a tool, the outcome to be predicted, the accuracy of the predictions made, the cost of the model and its software, and the availability of the data on which the model is run'.
http://www.nuffieldtrust.org.uk/sites/files/nuffield/publication/choosing_predictive_risk_model_guide_for_commissioners_nov11_0.pdf

Whichever option programmes choose, it is important to ensure there is a robust, ongoing evaluation and review process in place, involving commissioners, care teams and providers, to maintain the effectiveness of their programme. Procurements and contracts must account for this requirement for ongoing review.

3.3.5 Ten 'Top Tips' to consider for using risk stratification tool

The following tips are a sense check of easy to overlook aspects of risk stratification. They are adapted from *'A Guide to Implementing the Long Term Conditions Model of Care. Learning from the Long Term Conditions QIPP workstrea*m' (pp.10-11)

1. **Do take time** to understand the clinical and business needs for risk stratification and case finding so that you can build a solution that meets existing (and potential future) needs. Agree on the benefits you are trying to realise. Ensure your programme complies with IG and bring your IG colleagues into the programme at an early stage

2. **Don't use** the risk stratification data to replace local intelligence or clinical judgement – risk stratification tools are designed to be a useful addition to clinical judgement, not a replacement for it.

3. **Don't underestimate** the challenge of getting and sustaining clinical engagement. Working effectively on this area from the outset and managing it well can make a dramatic difference. Identifying and working with a clinical lead/champion will help tremendously.

4**. Do remember** this is about an end to end to end solution that starts with informing patients about the use of their data for risk stratification purposes, moves on to data extraction/collection, preparing it, running it through the tool, validating the outputs, making it available to users, training staff on how to interpret and use the data before it ends with managing the realisation of benefits.[9]

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[8] Lewis G, Curry N, Bardsley M. *Choosing a predictive risk model: a guide for commissioners in England.* London: Nuffield Trust, 2011.
[9] This will help you to comply with the fair processing requirements of the Data Protection Act – Principle 1

5. **Do include** primary care data. Algorithms that are based on just hospital data will successfully predict admissions or readmissions but incorporating data from GP practice systems will give a richer source of diagnostic information and will improve the performance of the risk stratification process.

6**. Do consider** how clinicians and others access the information and how user friendly the tool is – ideally they should be able to access information on their desktops and it shouldn't take more than three clicks of the mouse to get to the information they use.

7. **Do stratify** your whole population. There will be significant numbers of patients at risk outside the over 65 cohort. [10]

8. **Do use** the system to identify the highest risk patients and then ask yourself if you have provided them with all the basics – a care plan shared with all the relevant parties, vaccinations and medicines review.

9. **Do learn** from people who have already implemented successful risk stratification programmes and don't be afraid to recycle and update existing resource materials such as information sharing agreements.

10. **Don't forget** that at the end of the day any tool will produce data. It's what people do with this data and the changes they affect that will make the difference.

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[10] **Tip no 7** poses particularly challenges for a lawful basis for processing personal confidential data as there is tension with the 3rd Data Protection Principle around excessive processing. Working through patient communication, choice and management are key to covering this particular "Do". Remember your obligations to account for objections and dissent.

4. Specific Purposes of Case Finding and Risk Stratification

4.1 Identifying people at risk of unscheduled hospital admission

4.1.1 As stated earlier, Roland and Abel[11] have provided a detailed analysis of case finding, risk stratification and population segmentation in relation to reducing emergency admissions. In the illustration below, they point out that focusing only on the top 0.5% or-even 1% highest risk patients offers a relatively small opportunity to reduce emergency admissions. The pyramid top section shows how you would have to save 107% of all emergency admissions accrued by the 0.5% highest risk group in order to reduce emergency admissions overall by just 10%.
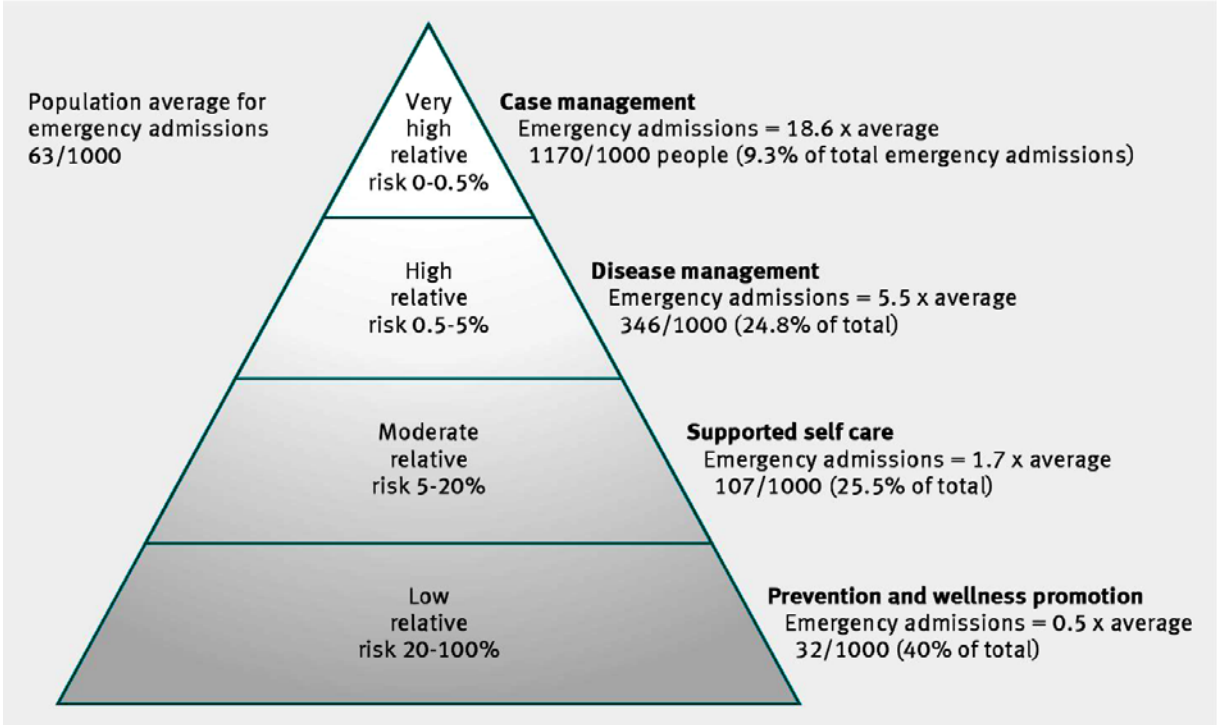
Furthermore, by confining your case finding to the highest risk segment of the population it is possible that the cohort identified already is very well known to primary care and social services and that care may already be optimised. Risk stratifying deeper into your population gives the opportunity to prevent more emergency admissions – not just because there will be more people but also because people at relatively lower risk of admission may present greater opportunities to bring integrated offers from social care and the voluntary sector to bear on existing input from health teams across primary, community and secondary care.

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[11] http://www.bmj.com/content/345/bmj.e6017

4.1.2 A report published in June 2013 by Kent and Medway Public Health Observatory,[12] provides analysis of risk scores that suggests approximately 30% of patients move out of the very complex risk band (0.5% of the population) within one month; 50% after five months and 80% after one year. Thus risk stratification results quickly become outdated. The report therefore proposes that *prediction* of a 'crisis year' and preventive intervention or approaches for the complex risk group could have a more significant impact on reducing unplanned admissions.

4.1.3 Promoting and incentivising case finding with GP practices for those at highest risk of unplanned admission

In 2013-14, NHS England offered an Enhanced Service Contract which incentivised volunteer practices to identify the top 0.5 – 1% highest risk cohort of adults on their list and offer them case management. For 2014-15, the '**Avoiding Unplanned Admissions: Proactive Case Finding and Care Review for Vulnerable People Enhanced Service'** is asking practices to use an approved risk stratification tool to identify the 2% highest risk group of patients. This includes under 18s with complex needs.

This enhanced service (ES) is designed to help reduce avoidable unplanned admissions by improving services for vulnerable patients and those with complex physical or mental health needs, who are at high risk of hospital admission or readmission. The requirements for the ES are that it should be complemented by whole system commissioning approaches so as to enable reduction of avoidable unplanned admissions. The ES commenced on 1 April 2014 for one year and is subject to review. A link to the **ES specification** is provided here

http://www.england.nhs.uk/wp-content/uploads/2014/08/avoid-unplanned-admissions.pdf

4.2   Methodologies for 'Harder to Reach' groups

4.2.1 Most of the current risk stratification methodologies rely partly or wholly on using diagnosis codes or READ codes to capture information about the risk factors and probability of future unplanned admission. There are a number of challenges associated with this. The inverse care law describes how people with the highest need for medical care may, paradoxically, find it hardest to access such care. If diagnoses are not coded due to problems with access or greater pressure on primary care in deprived areas then there will be an underestimation of some individuals' risk. One way of addressing this would be through the use of tools such as those for frailty identification, described earlier in **Section 2.**

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[12]   www.kmpho.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=303855

4.2.2 This will also be true in relation to any groups within a wider population who traditionally have poorer access to medical advice or uptake of NHS services. This applies to non-registered patients and can also apply to other groups such as people who are housebound, homeless patients and those with language barriers.

Where there is a cultural or societal reluctance to seek medical help for certain diagnoses – for example continence or mental health issues – these problems will be under coded and therefore the risk for some individuals will be underestimated.

4.2.3 Whilst using data from sources such as QOF registers in primary care can offer a good start in terms of reviewing significant multi-morbidity, each person's unique risk will be much more than the sum of the number of traditional "QOF" conditions coded as present. This is especially true for multi-morbid and frail patients where the presence of relatively minor or non-acute conditions on top of a number of significant long term illnesses can be predictive of enhanced risk. In these cases where the patient's homeostatic mechanisms are already taxed, additional diagnoses can be very important in adding to overall morbidity – and thus risk.

Advice note: The law around the use of information works on the basis of purpose, not of data set. Whilst you may have access to a data set you must be clear that you have a lawful basis for using the data set for a new or innovative purpose. Consideration of the use of QOF registers would fall into this category.

4.2.4 A decision therefore needs to be made about the **value of additional information to improve the performance of the risk calculation versus the effort required to collect those data.** Furthermore, risk stratifying only those patients with multiple long term conditions may restrict your interventions to a relatively small cohort of the overall population where the possibility of altering future outcomes will be variable. Risk stratifying the whole population will allow you to identify individuals and groups further down the "Kaiser pyramid". This opens up the possibility of finding people with risk factors who might be suitable for early intervention and prevention services, including self-management, healthy living and social inclusion opportunities run by local authorities or voluntary organisations.

5. Case Studies

5.1 Local initiatives using risk stratification[13]

5.1.1 In a recent review of models of care for long term conditions[14], NHS IQ identified examples of case studies where risk profiling is being developed for proactive management, for example, the 'Devon model' which has been found to be 86.5% accurate in predicting unscheduled admissions in the top 200 high risk patients.

Other places where there are examples are Leeds health and social care teams and in Kent, Barking & Dagenham.

5.1.2 The Central and Southern Commissioning Support Unit (CSU) – tool validation review

Central Southern CSU has been using the Johns Hopkins Adjusted Clinical Groups (ACG®) System as its risk stratification tool for over four years. The CSU has developed a huge amount of experience during this time, not just in terms of using risk stratification software but with the associated activities such as engaging with GPs and LMCs, primary care data extraction, information governance issues and most importantly developing a knowledge base that can be used to support both the clinical and commissioning agendas. See CSU slides

In collaboration with Johns Hopkins University, Central Southern undertook a recalibration exercise. The principal aim of the exercise was to apply ACG System variables (predictors) in Year 1 to predict individual patient outcomes in Year 2. Two main dependent (outcome) variables were used in the study: total cost in Year 2, and hospitalisation (inpatient admission) in Year 2. The objectives were to create predictive models based on data from the NHS in England, validate those models, compare these with the existing US-based models, and to recommend a model for application in the NHS based on these comparative results.

The results of the exercise show a statistically significant improvement over the existing models available in the ACG System. This is consistent with similar exercises carried out in Sweden and Spain. Subsequently, Central Southern have incorporated the recalibrated models into the version of the ACG System used in this the country and have also made this available to other ACG System users in the UK. The CSU's report can be found at:

http://www.cscsu.nhs.uk/case-studies-and-publications/risk-stratification/

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[13] To the best of our knowledge, projects in the case studies followed IG best practice and the lessons learned and shared are invaluable. The evolving IG landscape may have a bearing, however, on adoption of these examples in the future.

[14] A review of models and approaches to care and support for people with long term conditions, NHS Improving Quality (2013)

5.1.3 Central and Southern CSU - illustration on use of data

In Central Southern CSU, risk stratification, risk profiling and risk adjustment methodologies are being used to support:
- **case finding**
- **population profiling**
- **resource management** and
- **our understanding of relative performance.**

More information can be found here in the form of a presentation that summarises the current uses of the ACG System in the CSU and a case study illustrating how the use of case-mix adjusted benchmarking is helping a CCG to compare case-mix adjusted 'expected' levels of activity against actual levels.

CCGs and GP practices have been using the risk stratification tool (the John Hopkins ACG System) to identify patients most at risk of emergency admission. They also use the tool to identify patients at risk of high cost (who may not be at risk of an emergency admission) to offer these patients support and interventions to mitigate the risk. Other organisations use the risk stratification tool to find patients from lower tiers of the so-called risk pyramid. In Bath & North East Somerset the community services provider, Sirona, are using the tool to identify patients suitable for their health visitor-run 'Active Ageing Service'.
http://www.sirona-cic.org.uk

Sirona are also using the ACG System to gain a better understanding of morbidity profiles in older people and differences in how these distributions vary between different localities.

5.1.4 In Greenwich, GP Dr Junaid Bajwa from the CCG and Jackie Davidson from the Public Health team introduced a pilot in 2013 to improve the outcomes of patients on multiple disease registers through the introduction of RAG/risk stratification, prevention and supported/assisted management and support for self-management. They developed and are implementing a software MSDi Tool for managing people with co-morbidities. The tool aims to systematise and integrate care, thus improving the clinical outcomes and improving the patient experience. The focus is on the bottom part of the "health pyramid", identifying risk optimisation in primary care for patients with LTCs, as well as the high impact users in the top half.

The tool is also being implemented in practices in Bexley CCG. Work is in progress to formally analyse results. Information about the tool can be found here

http://youtu.be/he__szFTxrw *(12min video clip)*

Contact details for further information:
junaid.bajwa@nhs.net and david.murgatroyd@merck.com

5.1.5 West Leicestershire, East Leicestershire and Rutland, Leicester City CCGs – identifying higher risk patients

GPs are using the Adjusted Clinical Groups system to identify between 2% and up to 10% of the highest risk patients for primary care review. Subject to consent, patients will be reviewed and referred to Community Health and Social Care teams, Local Authority services and voluntary organisations for a range of interventions and opportunities to improve their disease control and general well-being.

5.1.6 Case Finding to support Multi Disciplinary Teams

Joint HSC teams in Halton LA have found that using **PRISM**, a health focused predictive model, has resulted in:
- Identification of individuals who could benefit from an MDT approach between health and social care.
- Proactive approaches for patients and carers including: rapid risk assessment for falls, avoidance of unplanned admissions and exacerbation of chronic conditions; creation of multi agency care plans; finding a more appropriate, safer housing environment
- Better consistency across joint health and social care teams, affording less fragmentation and duplication of assessments and care delivery processes
- Better identification when problems have roots in either health or social care (or more usually both)
- Opportunities for key stakeholders to discuss and problem solve together within a joint health and social care team meeting.

The Teams use a commonly agreed set of steps in a process for gaining patient consent to identification and selection for the MDT approach

5.1.7 The GRASP audit tools

This suite of audit tools includes Heart Failure, COPD and Atrial Fibrillation. It has been developed through partnerships between Primis at the University of Nottingham and NHS IQ. The tools are not algorithims. They are free to download and enable GP practices to interrogate their own disease register data. They have excellent case finding functionality, allowing quick search and review of whole case loads.

Further details and information about becoming a registered user are at   http://www.nottingham.ac.uk/primis/tools/audits/grasp-copd.aspx

5.1.8 NHS IQ identified a case study from the LTCs QIPP programme in which Southampton Community Healthcare used risk stratification tools, such as GRASP, to positively identify patients, with the result that they benefitted from a Community Atrial Fibrillation Service.

6. Information Governance

6.1 Implications for data sharing

6.1.1 The current context

As noted throughout this document, there are a number of challenges set by the current legal context around the use of patient data. Some of these challenges emerged with the change to the statutory and administrative structure of the NHS as a result of the Health and Social Care Act 2012. Others have been with us for some time.

In order to help GPs, their fellow clinicians, and commissioners evaluate the benefits of risk stratification (for case finding), NHS England submitted an application under regulations enabled by Section 251 of the NHS Act 2006. This is designed as a short-term solution to enable a process to be evaluated or for an alternative lawful basis to process patient data for a risks stratification purpose to be found. In most instances, the expectation is that consent will be considered, though this is challenging for "whole population" approaches. The application currently expires on 1 April 2015.

NHS England published guidance on Risk Stratification in 2013, which is currently being reviewed and supplemented with additional "how to" checklists. Updates and more information can be found at the following location: http://www.england.nhs.uk/ourwork/tsd/ig/risk-stratification/ as well as in the 'IG Bulletin' which can be found at: http://www.england.nhs.uk/ourwork/tsd/ig/ig-bull/.

Programmes are advised to keep an eye out for updates and changes. As more information becomes available NHS England will aim to make it available to colleagues throughout the system.

6.1.2 Current challenges for CCGs using patient data

Clinical Commissioning Groups (CCGs) were created as commissioning bodies and have the statutory duties, responsibilities and powers to perform that function. Case finding and risk stratification is not entirely commissioning nor is it entirely direct patient care (though it does enable it). Therefore, CCGs need to be very clear on the proposed purpose and manner of their programmes and how it will use patient data. This will require the organisation and its partners to consider which option is best suited for meeting their requirements and what needs to be done to enable this.

The key points to meeting these challenges are:

1. Starting from a patient focused direct-care perspective (how will this benefit clinicians in providing direct care to patients) and building outwards;

2. Working out what information is needed, where it is captured, and how it will flow between organisations. This is to ensure that a lawful basis is identified for each flow of data for each specified purpose;

3. How will patients be informed about the use, how will they exercise choice and how will this be managed;

4. Ensuring that the right controls and assurance is in place, and that the Data Controllers (often the healthcare providers organisations) can demonstrate that they "determine the purposes … and the manner in which any personal data are, or are to be, processed"[15];

6.1.3 Impact of Caldicott 2 on the Year of Care and other commissioning approaches

There are three key issues for CCGs, CSUs and Area Teams:

- Commissioners cannot assume that they are a data controller or that they have a lawful basis to access patient data or use it for a specified purpose. That does not stop them from being a data controller, if a lawful basis can be established, or from acting as a data processor if the right controls are in place;
- The use of patient data for purposes other than direct care needs to have a lawful basis and any data requested from providers will need to establish this lawful basis covering the Data Protection Act 1998, the Common Law Duty of Confidentiality and taking sufficient account of the Human Rights Act 1998 (Article 8);
- Commissioners cannot share any patient data without having a lawful basis to do so and must seek assurance that the flow of data is appropriate and secure, usually with a written control such as a contract or Information Sharing Agreement

Innovation and linking data sets is particularly challenging against this background. However, the Caldicott 2 review did not change the law or introduce new restrictions. It merely outlined the current obligations to patients and their information arising from the law, regulation and policy. For an example, see the NHS Constitution.

Patient consent is one of the key options to consider in planning approaches to these issues. However, programmes must ensure that consent is taken account of and that it is a genuine choice – so when a patient objects their data must be appropriately excluded from processing.

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[15] See Data Protection Act 1998, s.1, http://www.legislation.gov.uk/ukpga/1998/29/section/1

Meeting these requirements stalled the Year of Care programme around their work on the costing dataset which would enable identification of the LTC capitated budget. The Data Protection Act only applies to data from which patients can be identified, which would include the NHS number. The NHS number has previously been used as the 'key' to allow data from various sources to be matched to form a single patient record.

[Click here for more information on the Year of Care programme](#).

6.2 Case studies on data use

6.2.1 A solution recently developed in Kent, uses data pseudonymised at source (i.e. by the provider). Pseudonymisation has previously been rejected because it would no longer be possible to match records based on NHS number. However, if each provider uses the same pseudonymisation key, it should mean that the NHS number will be encrypted in exactly the same way by each provider. As long as no person-identifiable fields (such as the NHS number) are present, the data is not subject to the same IG restrictions and can be shared with the CSU and CCGs.

There is a national plan to resolve these issues through Section 251 agreements and submissions are currently being completed for the Confidentiality Advisory Group (CAG).

Pseudonymisation - Outline of Proposed Solution

- Each provider uses the same pseudonymisation key (this is likely to require the use of the same tool to ensure consistency in the results).
- The patient level data required should be extracted by each provider from their system(s) and compiled into a single spreadsheet (to be accessed only by their own organisation) according to the data collection template.
- The provider spreadsheet should be pseudonymised using the defined tool and key.
- The pseudonymised spreadsheet should be submitted to the CSU or to the Data Services for Commissioners Regional Offices (DSCRO) where it will be amalgamated with similar data from other providers. *http://www.hscic.gov.uk/dataservicesforcommissioners*

Key Principles

In order for this to be an acceptable solution, nobody should be able to identify any individual or any aspect of that individual's care beyond the information they would usually have access to within their own system. This means:

- The **CSU team** receiving this data must **NEVER** have access to the pseudonymisation key which would enable the reversing of the encrypted NHS number and so identify individuals.

- No data can be shared with any **provider** beyond what they would usually have access to, as they hold the pseudonymisation key and could therefore (at least in theory) identify individuals.

For further advice on this topic, contact David.wilcox@nhs.net (LTC Tariff Development Manager)

Connecting for Health – archived web advice on this topic can be found at http://webarchive.nationalarchives.gov.uk/20130502102046/http://www.connectingforhealth.nhs.uk/systemsandservices/pseudo

All CSUs are now on the Section 251 list of approved risk stratification suppliers and their tools/specifications have been verified.

6.2.2 Making data sharing work at CCG level – examples from the Year of Care programme

a) Kent Early Implementer Site: Whole Population Dataset Analysis Report

The Kent 'whole population' dataset and analysis, has linked whole population demographics with activity and cost data for the population from acute, community, mental health and social care providers, over a four year period. These data help to understand the impact of different selection methods for people with 'very complex' health and social care needs, particularly in relation to the Long Term Conditions Year of Care currency being developed by the Long Term Conditions Year of Care Commissioning programme. The main purpose for the initial analysis was to compare population stratification methods and to help define selection methods for people with 'very complex' health and social care needs. The analysis strongly supports research from elsewhere and builds upon this evidence.

Three methods of population stratification are mentioned in the paper:
- A Risk Stratification method, as described by the Kaiser Permanente pyramid;
- A Multimorbidity method, described the Scottish multimorbidity research programme;
- The Decision Support Tool (DST) method tested by the LTC Year of Care Commissioning programme Early Implementer teams.

The paper describes differences in the patient groups selected by the risk stratification and multi morbidity methods. However, it should be noted that there are sub-methods aligned to these, for example, each risk stratification IT tool may:
- use a different algorithm for calculating risk;
- calculate a different type of risk (e.g. 'risk of emergency admission in the next 12 months', 'risk of greatest total healthcare expenditure in the next 12 months');
- use different input data sources for its calculation.

Similarly, it is worth noting that there are different methods for calculating multi morbidity. The Scottish research programme identified 40 LTCs, mainly from Primary Care data; the Somerset work identified 49 LTCs using a wide variety of data sources (although again mainly from primary care). The DST work identified 20 LTCs using only hospital admission records.

The results of Kent's early implementer analysis were published in a report '**Population Level Commissioning for the Future' by NHS Improving Quality as part of the Year of Care resources.**
See   http://www.nhsiq.nhs.uk/resource-search/publications/population-level-commissioning-for-the-future.aspx

The LTC Year of Care Commissioning programme would like to compare results from these studies with results where multi morbidity was identified using the Quality and Outcomes Framework (QOF) clinical indicators, as this has the potential to be a nationally standardised selection method based on existing data. It has not yet been possible to do this in Kent using data for their interim report.

b) Kent and Medway: Data Sharing Approach
The current approach to intelligence and analyses of service utilisation is organisational based and limited, not taking into account the whole patient journey and effect across the system. The key initiative in Kent was to create a baseline profile of how intensive users have an impact on hospital services 'before, during and after their year of crisis' (alongside use of other services in the community and elsewhere) relative to service utilisation by the rest of the risk stratified population. This initiative provided not only the framework for developing local evidence for anticipated outcomes, i.e. the benefits of integrated care, but also the basis for evaluating and designing the local Year of Care Programme from 2013 onwards.

 An historical Kent & Medway population list was risk stratified, using the tool developed by the Kent & Medway Health Informatics Service (HIS) which hosts a regional data warehouse for hospital, community health and primary care data. Datasets from all services were linked to the risk stratified population list in the form of a 'hub and spoke' model using a pseudonymised patient identifier, i.e. NHS number. To comply with information governance, the pseudonymised and anonymised data sets were analysed by Public Health on condition that they could not be re-identified without unreasonable effort. As guiding principles the necessary data sharing agreements were drawn up and signed by the respective Caldicott Guardians to authorise the datasets linkage. The same methodology has been applied for the shadow testing phase of the Year of Care programme. Public Health has contracted the KMHIS to develop a customised dashboard that would help in this regard.

6.3 Use of Fair Processing Notices (FPNs)

6.3.1 Under the first data protection principle of the Data Protection Act 1998, data controllers are required to inform individuals whose data is to be processed of:

- the identity of the data controller

- the purpose or purposes for which the data may be processed

- any further information which is necessary to enable the processing to be fair.

This is known as a 'fair processing notice' but can also be referred to as a privacy notice. The notice should clearly set out an explanation about the purpose of processing or use of the information. In the case of the health and social care systems, the notice should enable people to know that their data is being used, for example, to benefit provision of care, whether this be planning, commissioning, delivering or improving services. The notice should be given well in advance and also include details of how individuals can find out more about the processing in question.

Where further data sets are required and this was not referred to originally, or where exemptions apply, it is recommended that new notices should be issued anyway.

Getting Fair Processing right: key things to remember

- Fair Processing and informing patients is not a one-off activity, it is an ongoing process that should consider the needs of the patient population
- Good examples are those that check material with patients through patient engagement and often take a layered approach, allowing key facts to be presented with increasing levels of detail for those that are interested
- Communication with patients about the use of their data should reassure them about its safety and the benefits of the use; it is part of the process of selling the benefits of your programme to the patients that will benefit
- Due to possibility of changing partners, providers and innovation, most fair processing programmes include an element of flexibility to enable them to cope with change without having to reissue all of their material.

The **Information Commissioner's Office** website has up to date information and advice on the Data Protection Act and on fair processing.

https://ico.org.uk/for-organisations/guide-to-data-protection/principle-1-fair-and-lawful/

6.3.2 South East Coast CSU - Key Learning

The GPs and CCGs working with South East Coast CSU had identified a variety of fair processing issues and the CSU has shared this case study:

Challenges:

- Many different fair processing notices were being used and applied in different ways. There was a lack of clarity about the requirement for them and how they should be used;
- Data controllers said they found it difficult to make sure patients were informed in a meaningful way;
- They had difficulty understanding when, and how, patients' information was processed and how dissent was applied within case finding and risk stratification tools.

Action:

The CSU IG Business Intelligence(BI) Deployment teams tried a number of approaches:

- using clear wording to define the Data Controller responsibilities in the Data Processing Deed of Contract;
- ensuring that at the point of implementation of the tool, the Data Controller is clear about their responsibilities by specifying the requirement **again** in writing and providing material (downloadable poster/leaflet and web text on FPNs) to reinforce the requirement;
- reinforcing the requirement at training sessions, working through application of dissent and ensuring the FPN has been applied in practices;
- GP Practices frequently discuss their approach with their Patient Forum to ensure FPN requirements for all areas are communicated in a clear way with patients.

What difference has it made?

- Using multiple channels and approaches with CCGs and GP practices has supported the practices to work with their patient forums /groups to shape their local FPN arrangements; see leaflet for patients on use of information
- the dual approach of BI deployment/training working closely with IG and data controllers has ensured consistent ,clear, action based messaging for Data Controllers;
- Having a clear understanding about how to apply dissent and how this is applied in the tool has provided Data Controllers with clear, easy action and confidence in applying their patient's dissent.

For further information, contact ivor.evans@nhs.net   at SE Coast CSU

6.3.3 Case Study from Waltham Forest, East London and City Integrated Care Programme (WELC Care Collaborative)

The Integrated Care Programme is made up of CCGs, providers and local authorities working across the footprint of the UK's largest trust, Barts Health NHS Trust. The partners in the Collaborative have a common set of principles for how they should integrate services locally, in response to feedback from patients, carers and staff.

In order to help partners meet the legal requirement for fair processing of personal and confidential information by organisations involved in commissioning and providing care, in an integrated, operational environment, Integrated Care Programme recently produced a strategy template for CCGs to use/adapt as needed.

A copy of the 'WELC Care Collaborative Integrated Care Programme Fair Processing Template Strategy for Partners 2014' can be downloaded here.

The programme will be adding further materials to support the strategy, including an animation that will sit on the CCG websites explaining how data is used.

7. Clinical Informatics Advice on Data Safety

7.1 Practical tips: Safe data systems and use of software

7.1.1 Ensuring appropriate reuse of data, records and coding standards

Encouraging data to be reused across the NHS will improve the data available to risk stratification algorithms. Primary Care is already experienced in using clinical coding, for example with Read Codes and the move to SNOMED CT. However, we need to broaden the range of data that is available for risk stratification and ensure that data is compatible across systems. This requires increased use of record and data standards and consistent coding of data.
For guidance on ensuring contracts with providers follow generic documentation standards see http://systems.hscic.gov.uk/clinrecords/cdgrs

Ensuring that the NHS Number is used is a national quality requirement. The NHS England Standard Contract 2014/15 requires that Service User Health Records should use the NHS Number. **Service Standard SC23** provides contractual standards for use of the NHS number and integrated care record use, in line with the Integrated Digital Care Record programme.

7.1.2 Making systems safe

ISB 0129 *'Clinical Risk Management: its Application in the Manufacture of Health IT Systems'*, describes the standards the NHS must follow to ensure that patient safety is maintained in clinical systems and any potential risk to patients is reduced. It includes managing risks in system design that may also be appropriate to apply across risk stratification, such as poor or confusing presentation of information or failure to use the latest data. See http://www.isb.nhs.uk/documents/isb-0129

7.1.3 Specification and use of open interfaces across the NHS

NHS England's vision of a people-powered health and care system – enabled by the integrated digital care record – requires an ecosystem of applications, data and processes working seamlessly to make the right information available to the right user at the right time. The systems underpinning this must also be affordable and sustainable. Open Application Programming Interfaces (APIs) have an important part to play in achieving this by making application functionality easily available, allowing the best system for the job to be chosen and promoting and accelerating innovation. See http://www.england.nhs.uk/ourwork/tsd/sst/the-open-api-policy/

7.1.4 **'The Integrated Digital Care Fund: Achieving Integrated Health and Care Records'** explains how integrated records can be the backbone for sharing and participation in healthcare. This NHS England strategy document shows how systems can enable risk stratification and case finding, through better use of information across the NHS.   See http://www.england.nhs.uk/wp-content/uploads/2014/05/idcr.pdf

8. Appendix 1 – Other useful resources and references

Better Care Fund Technical Guidance section on population segmentation, risk stratification and information governance.
http://www.england.nhs.uk/wp-content/uploads/2014/09/1-seg-strat.pdf

NHS England Advice for CCGs & GPs on Information Governance & Risk Stratification.
http://www.england.nhs.uk/ourwork/tsd/ig/risk-stratification/

NHS England IG Taskforce - Frequently Asked Questions on data sharing and Section 251 applications
http://www.england.nhs.uk/wp-content/uploads/2014/02/if-faqs-3.pdf

Section 251 (Health Act 2006) and the law – Frequently Asked Questions
http://www.hra.nhs.uk/documents/2014/02/cag-frequently-asked-questions-1.pdf

Enhanced service Specification: Avoiding unplanned admissions: proactive case finding and patient review for vulnerable people   NHS England Guidance document (July 2014)
http://www.england.nhs.uk/wp-content/uploads/2014/08/avoid-unplanned-admissions.pdf

Avoiding unplanned admissions enhanced service: proactive case finding and care review for vulnerable people. Version 3 June 2014. Guidance and audit requirements. (BMA, NHS England, NHS Employers).
http://www.nhsemployers.org/~/media/Employers/Documents/Primary%20care%20contracts/Enhanced%20Services/2014-15/Unplanned%20admissions/Avoiding%20Unplanned%20Admissions%20-%20Guidance%20and%20audit%20requirements%20for%202014-15.pdf

Please note that the guidance on the enhanced service is currently being revised – for updates, check the NHS Employers website.

Proactive care programme:
CCG support for implementation (NHS England guidance, May 2014)
http://www.england.nhs.uk/wp-content/uploads/2014/06/avoid-unpln-admss-ccg-guid.pdf

Population Level Commissioning for the Future (published August 2014 by NHS IQ, Kent County Council, Neil Wilson Associates (research from Kent Year of Care Early Implementer Site).
http://www.nhsiq.nhs.uk/resource-search/publications/population-level-commissioning-for-the-future.aspx

http://www.nhsiq.nhs.uk/resource-search/publications/population-level-commissioning-for-the-future.aspx#sthash.sF9hmNtD.dpuf

Improving end of life care through early recognition of need Exploring potential for using predictive modelling in identifying end of life care needs. (National End of Life Care programme, February 2013)
http://www.thewholesystem.co.uk/wp-content/uploads/2014/07/eolc_predictive_modelling_report.pdf

Using the Johns Hopkins' Aggregated Diagnosis Groups (ADGs) to predict 1-year mortality in population-based cohorts of patients with diabetes in Ontario, Canada.
http://www.ncbi.nlm.nih.gov/pubmed/22212006

Choosing a predictive risk model: a guide for commissioners in England. Nuffield Trust (November 2011).
http://www.nuffieldtrust.org.uk/publications/choosing-predictive-risk-model-guide-commissioners-england

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"Impactibility models": identifying the subgroup of high-risk patients most amenable to hospital-avoidance programs. Geraint H Lewis
http://www.ncbi.nlm.nih.gov/pubmed/20579284

How Health Systems could avert 'Triple Fail' Events that are harmful, are costly, and result in poor patient satisfaction. GH Lewis et al (April 2013)
http://www.ncbi.nlm.nih.gov/pubmed/23569046

The First Year: The Independent Information Governance Oversight Panel's report to the Secretary of State for Health (January 2015)
https://www.gov.uk/government/publications/iigop-annual-report-2014

This recent report looks at whether health and social care organisations are sharing information wisely and preventing improper disclosure of personal data

9. Glossary of abbreviations and terms

Better Care Fund a £3.8 billion pooled budget for health and social care services, shared between the NHS and local authorities, to deliver better outcomes and greater efficiencies through more integrated services for older and disabled people. The NHS will make available a further £200 million in 2014-15 to accelerate this transformation.

CAG Confidentiality Advisory Group provides independent, expert advice to the Health Research Authority (for research applications) and to the Secretary of State for Health (for non-research applications) on whether applications to access patient information without consent should or should not be approved under Section 251 of the NHS Act (2006). The role of CAG is to review applications and advise whether there is sufficient justification to access the requested confidential patient information. Using CAG advice as a basis for their consideration, the HRA or Secretary of State will take the final approval decision.

CALDICOTT 2 - a further Information Governance Review (the "Review") conducted at the request of the Government by Dame Fiona Caldicott and published at the end of April 2013. The original **Caldicott report**, published in 1997, established six principles for NHS bodies (and parties contracting with such bodies) to adhere to in order to protect patient information and confidentiality.

CCG Clinical Commissioning Group.

CSU Commissioning Support Unit.

CQUIN this is a Commissioning for Quality and Innovation payment to a provider, as part of a local or national scheme to secure improvements in quality of services and better outcomes for patients, whilst also maintaining strong financial management.

Fair Processing

"Fairness generally requires you to be transparent – clear and open with individuals about how their information will be used …"

"Processing" broadly means collecting, using, disclosing, retaining or disposing of personal data, and if any aspect of processing is unfair, there will be a breach of the first data protection principle under the Data Protection Act 1998– even if you can show that you have met one or more of the conditions for processing."

See the Information Commissioner's Office website
https://ico.org.uk/for-organisations/guide-to-data-protection/principle-1-fair-and-lawful/

IG Information Governance.

HSCIC the Health and Social Care Information Centre. Trusted national provider of high-quality information, data and IT systems for health and social care.

PARR tools 'Patients at Risk of Re-hospitalisation' algorithims that use inpatient data to produce a 'risk score' showing a patient's likelihood of re-hospitalisation within the next 12 months.

QIPP 'Quality, Innovation, Productivity and Prevention' – initiatives that aim to make savings for the NHS at the same time as delivering improvements in quality of care.

QOF Quality and Outcomes Framework.

READ codes a set of clinical codes designed for Primary Care to record the everyday care of a patient

SNOMED CT (or Systematised Nomenclature of Medicine--Clinical Terms) is a comprehensive clinical terminology, originally created by the College of American Pathologists (CAP) and, as of April 2007, owned, maintained, and distributed by the International Health Terminology Standards Development Organisation (IHTSDO), a not-for-profit association in Denmark.

Year of Care the Year of Care programme is a partnership between NHS Improving Quality, Diabetes UK, RCGP, and the Quality Institute for Self Management Education & Training (QISMET) that aims to provide personalised care planning for people with long term conditions by working in partnership with patients and care professionals.