Dear Health & Sport Committee members

Many thanks for the opportunity to give evidence at the recent inquiry. I write following a request to provide the committee with two reports which I mentioned may have benefited from a more focused and resourced clinical leadership than has been available to date.

1. Report on Anticipatory Care Planning for Scottish Government and the eHealth Directorate
2. Report on the Key Information Summary (KIS) for the Scottish Government eHealth Directorate.

Both commissions were carried out in 2016 by National Services Scotland IT at the request of the Scottish Government. This followed a number of meetings raising awareness of the current and future challenges of robustly communicating Anticipatory Care Planning (ACP) information for patients across Scotland (and more widely throughout the UK).

The ACP commission report went to the Scottish Government’s eHealth team in September 2016 and the KIS commission report was available in May this year. The clinical oversight for the work has come from a number of different areas supporting the Scottish Government directorates of Person Centred Care (Living Well in Communities) and Palliative and End of Life Care.

The reason for raising the issue of resourced clinical leadership as a concern is that this hugely important work requires strong clinical leadership and expertise, which to date has only been piecemeal. Input has been provided, in part, by Health Improvement Scotland’s (HIS) ACP clinical leads and from a number of other clinicians including myself who do this in personal time alongside numerous other non-clinical work priorities. It has therefore not received the level of focus and clinical leadership that it certainly warrants which has, I feel, made progress on visible results frustratingly slower than could otherwise have been.

A workshop supported by NSS IT and the Scottish Government is planned for the New Year to build on the work of these commissions, which is welcome. The HIS funding for the ACP clinical leads comes to the end of its two year commitment shortly, which will further reduce clinical input in this area and so this would be a very helpful time to seek clarification about how appropriate clinical leadership for this work is going to be resourced moving forward.
The Commission to evaluate the eHealth connectivity of Scottish Hospices is the other work that I mentioned and the Terms of Reference for this Commission are still being finalised. Ensuring that any recommendations made from this commission are actioned, shared and embedded would be another example of where I feel strong and visible clinical leadership would be hugely helpful and effective given that the actions will span third sector, NHS, NSS IT and the Scottish Government.

Best wishes

[Signature]

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Report on
Anticipatory Care Planning
for Scottish Government
eHealth Directorate

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Last Updated: 15th September 2016
Version: v1.1
Status: Commercial in Confidence
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Executive Summary & Introduction

This Scottish Government eHealth Directorate commission, “ACP in Scotland - Information Sharing Requirements”, is being undertaken by National Services Scotland Information Technology (NSS IT). The work of the commission is to investigate how Anticipatory Care Planning (ACP) information held in the GP IT systems is shared, not just within Primary Care services, but primarily with respect to ACP information being used and accessed beyond the Primary Care boundaries with Secondary Care services, Out of Hours services, Hospices, and Social Care.

Dr. Catherine Calderwood, the Chief Medical for Scotland, makes reference in her CMO’s Annual Report for 2014-15\(^1\) to the need for collaborative, relational decision-making and planning at the heart of the healthcare system.

The Scottish Government recently produced ‘A NATIONAL CLINICAL STRATEGY FOR SCOTLAND’ (Feb 2016)\(^2\), in which a number of points refer to Anticipatory Care Planning. Reference is made to the use of technology and IT to underpin a number of key changes in Primary and Community Care: “Electronic information sharing will facilitate collaborative working across integrated health and social care teams to best support people’s needs. People and their GPs will have access to electronic patient records and patient held information from medical devices and other consumer products to help them manage the individual’s health and social care needs and agree outcomes which are then recorded in electronic anticipatory care plans”\(^3\). A primary care pilot study in 2010, aimed at reducing unplanned hospitalisation using ACPs, is summarised, demonstrating the benefits to patients and reductions in both inpatient admissions and hospital bed days\(^4\).

The work undertaken by NSS IT on this commission is closely linked to the ACP work being led by a recently formed Healthcare Improvement Scotland (HIS) team, which is aligned with the NHS Quality Strategy for Scotland, the 2020 vision and the National Health and Wellbeing Outcomes supporting Health and Social Care integration. Their work is placed within the Scottish Government’s ‘Living Well in Communities’ initiative\(^5\).

The main findings and proposals documented in this paper are drawn from a) around 20 interview-style discussions with GPs, subject-matter experts, experienced ACP practitioners, and other Health and Social Care professionals (H&SCPProfs); and b) a series of ACP Focus Groups organised by HIS for a diverse group of Lanarkshire H&SCPProfs. Further details of the roles and organisations involved are detailed in the Acknowledgements appendix.

Three conflations\(^6\) were observed. Firstly, of KIS (Key Information Summary)\(^7\) and ACP (Anticipatory Care Plan)\(^8\), therefore information provided for this report required some additional knowledge and educated assumptions. Secondly, there is no separation between the

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\(^2\) ‘A NATIONAL CLINICAL STRATEGY FOR SCOTLAND’ \url{http://www.gov.scot/Resource/0049/00494144.pdf}

\(^3\) Ibid. page 51

\(^4\) Ibid. page 56. The ACP pilot study article was used by British Journal of General Practice (February 2012)

\(^5\) \url{http://ihub.scot/a-z-programmes/lwic-anticipatory-care-planning/}

\(^6\) Conflation: when two or more concepts share some characteristics, where they appear to have a single identity, and where their distinct differences seem to be lost

\(^7\) KIS is a component of the national ECS system

\(^8\) Anticipatory Care Plan information is entered as part of the KIS record within a GP IT system
patient’s personal ACP content and a GP’s clinical ACP content, leading to ambiguity. Thirdly, of the Plans and the Planning process, which conceals the individual importance of both the conversation between the two experts, and the information captured. This is expanded in the Scotland’s House of Care appendix, which is also referred to within the CMO’s report.

The ACP information currently held by GPs contains a mix of non-clinical information belonging to the patient, and some clinical information. One key proposal, from a large amount of passionate feedback, calls for an opening up of the GP IT Systems’ ACP content to enable all H&SCP rofs, and potentially patients and their carers, to have bi-directional (read and update) access to ACP information. This would introduce multiple bi-directional data flows, therefore guaranteeing the provenance⁹ of a patient’s record would be essential. It is beyond the scope of this commission to comment on the benefits or risks associated with particular proposals. Enhancements to the GP IT Systems that are not related to the recording or sharing of ACP content are not considered as part of this commission.

Contributions to this report came from a variety of disciplines, organisations, and Boards, across different sectors. A flavour of the people and organisations involved are included in the ‘Individuals and Organisations contributing to the ACP Commission’ appendix.

⁹ Provenance: the chronology of the ownership, custody or location of a historical object
Background

Anticipatory Care Planning has been a topic of interest for many years. The Scottish Government produced an “Anticipatory Care Planning: Frequently Asked Questions” document in Nov 2009\(^{10}\), updated in April 2010\(^{11}\), which focuses more on the patient’s current clinical context, and less about capturing future and End of Life care preferences or domestic information. The report notes: “At present there is no easy way for information on Anticipatory Care Plans to be shared between different clinicians. Anticipatory Care Plans need to be shared with the full range of care providers involved, including NHS 24 and Out of Hours Services, so that all are aware and can respond to the expressed wishes. The current system relies on a confusing array of 'special notes' faxes and emails from GP practices to Out of Hours Organisations, Accident and Emergency and admissions units.”

Since 2014, the Key Information Summary has filled some information-sharing gaps within NHS Scotland; however some significant gaps are well known, particularly beyond NHS territorial boundaries.

In January 2016, a Scottish Government eHealth SBAR on ‘Palliative Care and Anticipatory Care Planning (ACP)’ was used as a discussion tool for informing three commissions on ACP, KIS and ECS. The SBAR noted the following:

“KIS has been in use by all GP practices since 2014. Uptake has exceeded expectations and as its value has become clear there is mounting pressure to provide both additional information and more widespread access. There is also recognition of the challenges experienced by clinicians around KIS.

“It is also becoming clear that the level of new functionality required in support of a range of evolving policy initiatives cannot be delivered through the current ECS technology. For example, the ECS system was designed to be updated only by the GP practice system whereas future care models will require input from the integrated, multi-disciplinary team and the patient” (emphasis added).

In March 2016, Eddie Turnbull, Head of Scottish Government eHealth, highlighted the focus on Care Planning to the eHealth Scotland conference as part of his “Delivering the eHealth Strategy” presentation (March 2016) – see the Care Planning @ eHealth Scotland appendix.

In April 2016, the SG eHealth Directorate commissioned National Services Scotland Information Technology (NSS IT) to undertake three pieces of work on ACP, KIS and ECS.

Specifically, this commission seeks to identify representative ACP Information Sharing scenarios between H&SCProfss both within and beyond NHS Scotland. The main commission output - this report - is focused on ascertaining how the ACP information is currently provided, and the challenges experienced with sharing ACP information across technical, political and geographical boundaries.

ECS, KIS, ACPs, ePCS explained

The [national Emergency Care Summary (ECS) system](http://www.ecs.scot.nhs.uk/) was rolled out nationally in 2006. It has several distinct components, with a degree of overlap. Current medication and allergies information is uploaded from all NHS Scotland GP IT Systems into ECS. ECS content is made available to many emergency, Unscheduled and Out of Hours teams covering a range of scenarios.

The [electronic Palliative Care Summary (ePCS)](http://www.ecs.scot.nhs.uk/epcs-palliative-care) was rolled out in 2010 as an extension of ECS. GPs enter Palliative Care information into the ePCS component within their IT systems. This information is contained as a distinct in section of a patient’s ECS record, in addition to other ECS information and KIS.

The [Key Information Summary (KIS)](http://www.ecs.scot.nhs.uk/kis) was rolled out in 2013 as a further extension of ECS. KIS information is also entered into GP IT Systems and uploaded into ECS. The KIS dataset contains information including a patient’s demographics, medical history, current situation, Self Management Plan, Anticipatory Care Plan, resuscitation preferences, Preferred Place of Care, and Palliative Care arrangements. KIS information is contained as a distinct section of a patient’s ECS record, in addition to other ECS information, such as Current Medication and ePCS.

Anticipatory Care Plan (ACP). GPs enter ACP information into the KIS component within their IT systems. ACP information, created from the "Special Notes" and coded information, is uploaded to ECS as part of the KIS section, which enables further information about an individual to be more accessible.

Associated Work

Surveying the ACP landscape reveals that many initiatives have been launched, many meetings have met, and many articles have been written. There is a large amount of work being done to improve Care Planning in general, and Anticipatory Care Planning in particular. Some related work is noted here:

- ACP-focussed service development work, aligned with the Scottish Government’s ‘Living Well in Communities’ (LWIC) initiative, is being led by the new Healthcare Improvement Scotland (HIS) ACP team, which has clinical and nursing expertise from Dr Stuart Cumming (clinical project lead), Janette Barrie, and Sheila Steel. This work seeks to drive the development and uptake of ACPs.
- Some ACPs in paper form are held by the patient; others are retained by H&SCPProfs. These forms vary in content and design. As part of continual improvement, many forms go through design reviews to stimulate a higher level of adoption by refining the content and layout. This was a key element of the Lanarkshire ACP Focus Groups.

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12 [http://www.ecs.scot.nhs.uk/]
13 Most GP Practices upload several times every day; others every two hours; some less frequently
14 [http://www.ecs.scot.nhs.uk/epcs-palliative-care]
15 [http://www.ecs.scot.nhs.uk/kis]
Some paper forms in current use are acting, either similarly or equivalently, as ACPs while holding bespoke titles such as ‘My Thinking Ahead, My Making Plans’\(^\text{16}\) (MTAMMP – pictured on previous page)

A single patient-held ACP template is being drafted by the HIS team. This is likely to be tested first in one NHS Scotland Health Board across all H&SCProfs, with national dissemination tofollow later.

**ReSPECT (ECTP):** Associated work on the “**Recommended Summary Plan for Emergency Care and Treatment**”, (pictured), previously called “Emergency Care & Treatment Plan” (ECTP), is progressing towards an agreed template for use across ‘NHS-UK’. The ReSPECT) form and associated process have been developed to widen the shared decision-making conversation, for all patients including children and young people, beyond CPR/DNACPR to include other resuscitative measures. The multi-nation working group has prepared a sample form, with the intention that all UK NHS entities use the same template\(^\text{17}\). NHS Scotland continues to engage and will consider the potential for this as a national initiative. Dr Juliet Spiller, Marie Curie Hospice and NHS Lothian, represents NHS Scotland’s interests, and Blythe Robertson (Policy Lead for the Scottish Government’s Person Centred Care Directorate) will assess options on how this might be progressed.

**SCET** have been commissioned to build an application for patients to compile their own ACP content\(^\text{18}\).

Practice transfers: a ‘GP2GP’ process to transfer patient records between practices is under development, which would ensure retention of ACP information.

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\(^{16}\) Further info on ‘My Thinking Ahead, My Making Plans’ can be found here: [http://www.palliativecareggc.org.uk/acp/](http://www.palliativecareggc.org.uk/acp/)

\(^{17}\) Further info on [https://www.resus.org.uk/consultations/respect/](https://www.resus.org.uk/consultations/respect/)

\(^{18}\) An app was designed speculatively (c. 2012 by another supplier) with functionality to enable any H&SCProf to view KIS / ACP information. This proposal was not adopted by NHSScotland.
ACP Terminology

There is a noticeable variation in how similar terminology is used in the Care Planning context. Although there are similarities between an ‘Advance Care Plan’, an ‘Advanced Care Plan’ and an ‘Anticipatory Care Plan’, they have each been used synonymously, yet what each one describes can differ significantly from the others.

For example, an ‘Advance Care Plan’ can be a piece of paper that a patient brings on first visit to a Hospice, which a Palliative consultant may then use to prepare an ‘Anticipatory Care Plan’. An ‘Advanced Care Plan’ is a term used by some Nursing in Community teams to describe the plan that is put into place when a patient’s condition deteriorates to an ‘advanced’ stage. And an ‘Anticipatory Care Plan’ has different meanings to many different disciplines. An ‘Advance Directive’ is a document prepared by a potential patient or their lawyer in advance of future care. It contains less information than an ACP, but the information is useful for producing an ACP. A ‘Mental Health Advance Statement’ (MHAS) is a document owned by a patient within the Mental Health system and completed when they are well, with free-text content similar to an ACP.

Some Secondary Care teams have created their own internal documents; two Health Boards refer to these as a hospital KIS, or HKIS, and a hospital ACP. There are many other similar documents in other Health Boards, which are widely known as Treatment Escalation Plans. The hospital ACP supersedes the “Ceiling of Treatment Plan”. These local forms add to the confusion around terminology, source and content of KIS & ACP. Where an HKIS or Treatment Escalation Plan exists, the content is often retained within the hospital and not passed back to the GP for update into the patient’s GP record for subsequent uploading to the National ECS system.

In some Health Boards, different ACP templates are used for specific conditions (for example, COPD, Heart Failure, EOL), therefore some patients could have multiple ACPs in addition to the GP IT System ACP and the community based ACP paper forms. At least one Health Board uses combined terminology of “Advance / Anticipatory Care Plan”.

Care Homes and other organisations develop their own version of Care Plans.

With all the variety of forms, it is evident that the content of an ACP form in use for any one patient is unlikely to match the content held in other forms or the ACP information held by the GP.

Anticipatory Care Plans are increasing in visibility and usage throughout the UK nations and across separate NHS, Hospice, and Social Care entities. Beyond Scotland, other UK nations have chosen to use the term ‘Advance Care Plan’, while some H&SCProfs in Scotland believe the word ‘Anticipatory’ is not a helpful distinction within the Care Planning arena. The ECS website notes that KIS provides support for patients with electronic Anticipatory Care Plans (eACP). Within this document, ACP will refer to the ‘Anticipatory Care Plan’ from this point forward.

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19 An ‘Advance Directive’ is also known as a ‘Living Will’, which can be verbally stated in Scotland.
What is an Anticipatory Care Plan?
An ACP is created for specific patients. A patient can request an ACP; a GP may create an ACP for a patient who would benefit; and Primary Care practices use their SPARRA cohort to identify patients most likely in need of an ACP. Some of the different types of ACPs are discussed here.

GP Practice ACPs
Practice-based GPs and staff generally perceive that an Anticipatory Care Plan is the content stored in the ‘Special Note’ field, along with some automatically codified information. The Special Notes field is accessed from the ‘KIS’ tab in the Practice’s GP IT system. Access to ACP content within some Practices is limited to GPs alone, whereas other Practices have enabled most of their staff to create, update, or view any patient’s ACP content. The ‘Anticipatory Care Plan’ field may note the existence of an ACP, but this is relatively ineffective in an Acute system since the ACP ‘Special Notes’ content – the real ACP content - is less accessible to the Acute user.

ACP content is typically sourced from either:

- A discussion between the GP and the patient (or family member or other representative where the patient does not have capacity)
- Information extracted from letters issued by Secondary Care to the patient’s Practice
- Relevant information from within the GP’s patient record such as Special Notes
- Information from a practice-based or community nurse

The current methodology has resulted in a high sense of ownership by the GP community. This will continue to be reinforced by the ongoing desire to increase the capture of ACPs by GPs. Practices are generally seeing a month-on-month increase in the number of recorded ACPs. The HIS team are considering a target of 5-6% of the population\(^20\) to have an ACP.

One significant restriction in creating high quality ACP content is the size limitation of the Special Note field, which can require information to be condensed\(^21\).

Community ACPs
Community based practitioners from both Health and Social Work generally perceive that an Anticipatory Care Plan is the paper document, often held by the patient. Some of this content may also be entered into the GP IT System by Community or District Nurses.

The source of these ACPs comes from a discussion with the patient. Information is written down either by the patient or the H&SCProf during or after the discussion. This paper document can be updated by the patient and multiple H&SCPros. Maintaining an electronic record of updates is still preferred by some despite the associated challenges, particularly when paper copies require to be retrieved from, and reissued to, multiple parties for each and every change in content.

\(^{20}\) From “Anticipatory Care Planning in Scotland” (ACP Abstract 31): “Population stratification estimates that 5-6% of the population could potentially benefit from ACP. 2% of the population, (high-resource individuals), utilise 77% of hospital inpatient days and 50% of combined prescribing resources.”

\(^{21}\) The Special Note field can only hold 2,048 characters
There is often a dependence on a nurse or GP to enter information from a paper ACP into the GP IT system.22

**Children & Young Persons**

The ‘Children and Young Persons Acute Deterioration Management’ (CYPADM) plan exists to cater for specific needs of Children and Young People. In a general sense, a CYPADM is similar to an adult’s DNACPR. Further information on the SG’s policy on DNACPR and CYPADM is available here23.

The existence of a DNACPR form indicates an advance decision that cardiopulmonary resuscitation (CPR) will either not be effective or is not wanted by the patient. The CYPADM and DNACPR forms are often incorrectly seen as having the same purpose and containing the same content, which carries significant risk of confusion. While they share the same broad purpose of holding resuscitation preferences, the content can be significantly different. The CYPADM ‘includes decisions about wider resuscitative measures’, and the patient chooses from six Resuscitation options. DNACPR is the least selected preference. A wrong assumption solely based on the existence of a CYPADM potentially results in incorrect treatment, often at the time when the Child or Young Person is at greatest need of resuscitation. Earlier reference to ReSPECT (above) notes the intention to widen the shared decision-making conversation, for all patients including children and young people, to include other resuscitative measures beyond CPR/DNACPR.

The CYPACP, similar to NHSScotland’s CYPADM, is a “Children and Young Persons’ Advance Care Plan” template24, developed by the “CYPACP Collaborative Working Group” (NHS England based).

**Private and Third Sector ACPs**

Various organisations (for example, Nursing Homes; Macmillan) use their own forms, designed to capture information according to their own organisation’s UK-wide corporate standards. Specific application to the Scottish milieu often requires a degree of ‘tartanisation’.

An example of third party ACPs is Macmillan’s Scottish booklet (pictured), which contains over 80 pages of useful information and two forms documenting “What’s important to me” and a “Checklist for planning ahead”.

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22 Community ACPs in Lothian can be emailed to practices and imported without retyping
24 A CYPACP template and further info can be found here: [http://cypacp.nhs.uk/](http://cypacp.nhs.uk/)
One barrier to using ACPs more fully in Care Homes is the issue of many residents not having full capacity. This fact reinforces the benefit of people completing an ACP when they have capacity.

**Mental Health Advance Statement**

A more formal approach with legal backing is used in Mental Health. The Mental Health Advance Statement (MHAS) is an important statutory document under the Mental Health Act. While a MHAS has to be countersigned by a Health Professional or a Solicitor, it does not need to be made visible before health care is required. The Mental Welfare Commission for Scotland produced [guidance on good practice](http://www.mwcscot.org.uk/media/128044/advance_statement_final_version_jan_2014.pdf) in 2014. MHAS content is mostly free text, and does not hold DNACPR.

There is a separate ACP for Adolescents and Children who are involved in Mental Health services (CAMHS), which includes Health Visiting School Nursing.

GPs do not have direct access to Mental Health systems; detailed Mental Health information is not normally held by the GP, or is likely to be inadequate in detail; and existence of an MHAS is unlikely to be recorded by GPs. Awareness of a patient’s MHAS by front-line staff such as Paramedics, NHS24, Social Work, A&E, and GP Out of Hours (GP OOH) is scarce, but these front-line staff would benefit from seeing Advance Statements.

The Advance Statement is owned by the patient, and they make the decision on whether to share it with H&SCProfs or not. The existence of a MHAS may be recorded along with its location, but the NHS does not have implicit permission to store a copy. Statements held by NHS are normally stored electronically, but could also be in paper form. There is no consistent way to store MHAS content within the Mental Health systems at present.

If a patient with a MHAS becomes unwell, there is an expectation that their preferences will be followed by all H&SCProfs. As with ACPs, H&SCProfs should follow the MHAS, or be able to fully justify why they didn’t do what the patient had documented. This can be challenged at a Mental Health Tribunal who will validate actions against an Advance Statement.

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ACP content

Without exception, the content of ACPs is appreciated by H&SCProfs who want to use the content to determine how to provide the best possible care for an individual aligned to the patients’ wishes. H&SCProfs being able to view ACP content reduces the need for them to start a discussion of sensitive matters at a difficult time.

There is no specific guidance or contractual requirement on what content should be entered into an ACP, although some GPs suggest that the broad principles are clear enough and therefore they know what to do. It is essential that the process helps people to understand and think about what they want their life to look like. It can be difficult for a GP to ask these questions as patients often see the GP as the expert and expect them to know what is best.

Depending on an individual’s role, and the patient’s condition, the most important content cited varies considerably. The often-quoted information items include the following:

- Knowing the individual’s wishes and preferences e.g. ED admission v staying at home
- Ceiling of Treatment Plan
- Resuscitation preferences
- Next of Kin; family contact details; Power of Attorney

It seems important to reiterate that the key pieces of information are focussed on the patient’s preferences. There is general acceptance that the patient’s wishes should always be followed as specified unless that is impossible or clearly unadvisable: see the Legislation and Binding content section. Improving the quality of data and confidence of the people will require context sensitive recording of content in their own language. Adequate time is required for H&SC professionals to be with people to work through what they want. Some practitioners believe that encouraging people to arrange their Power of Attorney and a Will are more important than some of the planning.

The ACP content coming from GP Practices is always dependent on the GP choosing the most appropriate information from various sources and adding that information into the ACP field. Depending on the amount of information received, the process to update GP IT patient records can be very time consuming to complete properly, taking GPs over 30 minutes at times. Many believe this is unsustainable given the potential increased pressures on Primary Care services.

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26 The Ceiling of Treatment Plan is generally perceived by staff as very helpful; however the use of that terminology has declined due to the perception that full treatment was being withheld from patients against their best interests. It is also known as ‘Levels of Treatment’ and ‘Treatment Escalation Plan’.

27 Note earlier comment where the confusion about resuscitation of children and young people can arise with the existence of a CYPADM.
Accessing and Sharing ACP Information

Depending on the type and format of an ACP, it can be created, updated, and retained either by patients, H&SCProfes, GPs, or other Care organisations. This section focuses on how the ACP content entered into a GP IT System is shared beyond a patient’s practice via ECS.

- ACP information is shared with ‘GP OOH’ services via the national ECS system and Adastra; restricted to patients who have appointments allocated by the Primary Care Emergency Centre (PCEC) system
- Police Custody and the Prison Service (restricted to GPs and NHS Nurses) also have access to ACP information held in ECS via Adastra
- Both Scottish Ambulance Service (SAS) and NHS24 receive information feeds to identify patients who have KIS content in their ECS record
- Access for Secondary Care staff is variable and mostly dependent on Health Board, Role and Specialty. Areas with routine access to ACP information via ECS include A&E, ED, Acute Medical Units and other front door services, and Hospital Pharmacy.
- Many disciplines similar to those mentioned above such as Community Pharmacists and Nursing in Community do not have any access to ECS
- Most organisations external to NHSScotland do not have any access to KIS content via ECS

ACPs and GP IT Systems – a GP Centric illustration
### ACP Information Sharing Use Cases

The following high-level Use Cases describe how ACP content is created and viewed.

<table>
<thead>
<tr>
<th>Use Case</th>
<th>User</th>
<th>Access via ECS</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. GP – in practice</td>
<td>GP</td>
<td>Create / update / view</td>
<td>Discuss preferences with patient where possible; record in GP IT System (ACP field); add other information previously captured in other parts of the GP record.</td>
</tr>
<tr>
<td>2. GP OOH</td>
<td>GPs</td>
<td>View</td>
<td>View ACP (all KIS / ECS) content via Adastra for all patients within the Board.</td>
</tr>
<tr>
<td>3. Acute view</td>
<td>Consultants; Junior Doctors; etc</td>
<td>View</td>
<td>Dependent on local permissions, ACP content may be viewed from within a PAS or a Clinical Portal’s KIS section, although even where access is provided, there is a limited general awareness among Junior Doctors. With a lesser number of populated ACP records than ECS or KIS records, and therefore less cause for Junior Doctors to view ACPs, it is even less likely that Junior Doctors would come across ECS records that contain an ACP.</td>
</tr>
<tr>
<td>4. Acute update</td>
<td>Consultants via GP</td>
<td>Update</td>
<td>Updates are done by GPs on receipt of letters into the patient’s KIS / ACP (between a few hours or several weeks after discharge), however some information can be erroneously omitted.</td>
</tr>
<tr>
<td>5. NHS24 (1)</td>
<td>Call Handlers</td>
<td>None</td>
<td>Call handlers are classed as non-clinical therefore cannot access ACP content at present.</td>
</tr>
<tr>
<td>6. Scottish Ambulance Service (SAS)</td>
<td>Call Handlers</td>
<td>None</td>
<td>Call handlers are classed as non-clinical therefore cannot access any ECS content at present.</td>
</tr>
<tr>
<td>7. Ambulance crew</td>
<td>View</td>
<td>Access to ACP and KIS content is normally available within ambulances.</td>
<td></td>
</tr>
<tr>
<td>8. Paramedics e.g. via Motorcycle or car</td>
<td>Partial</td>
<td>PRU staff are able to see that an ACP exists but cannot access ACP information from KIS until an ambulance arrives.</td>
<td></td>
</tr>
<tr>
<td>9. Various trained members of the public</td>
<td>None</td>
<td>No access</td>
<td></td>
</tr>
</tbody>
</table>
ACP Access Challenges

The following details are representative and do not exhaustively cover all scenarios across NHSScotland.

- Practice based GPs depend on non Practice-based staff to feed relevant information back for manual update of the patient’s record.
- GPs and other Practice staff: some practices allow multi-disciplinary access to GP IT Systems; others limit access to GPs requiring more time and effort from GPs and causing delayed updates.
- GPs OOH or On Call: There are 14 separate ‘instances’ of Adastra in NHS Scotland, with data held in separate databases. Information such as past consultations will be restricted to those that have occurred in the same territory as the GP is currently based.
- Hospital based access to ECS / KIS varies across NHSScotland: some Boards use Role Based Access Control (RBAC) to provide access for various staff groups (e.g. Medical, Nursing, Pharmacy, AHPs, Records); other Board/s only provide access for Consultants, therefore requiring non-Consultant staff to access information via a Consultant.
- Non-Practice community based staff such as District Nurses and other AHPs can have limited or no access to GP IT systems.
- Scottish Ambulance Service call-handlers are unable to access ACP content held within the KIS record as they are not ‘clinical’ staff. Inadvertent advice on CPR against patients’ wishes can cause considerable upset. SAS Clinical Advisors, specially trained paramedics, have access to KIS and are involved in approximately 2% of calls.

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28 Some NHS Boards have initiated projects to enable access for CPs.
• NHS24 call-handlers are unable to access ACP content as they are not ‘clinical’ staff. Additional advice can be sought from Clinical Supervisors. An NHS24 call handler only knows if there is any relevant ACP or KIS content by phoning the Clinical Supervision Line to speak with a clinical ‘expert’ with access to the KIS record. However...
• NHS24 clinical staff cannot view ACP information for some KIS records, for example, where there appears to be a KIS record available but it is not accessible. Further investigation is required to determine potential causes. NHS24 expressed a desire to access other information such as IDLs and Final DLs.
• Scottish Ambulance Service has successfully introduced ACP access into ambulances but non-ambulance access is limited. For instance, a motorcycle paramedic can see that an ACP exists, but needs to wait for an ambulance to arrive before viewing the ACP information held in the KIS record.
• Social Care. H&SCProfs employed by Councils, including some AHP roles, do not expect to have equivalent access as NHS staff in the same discipline.
• When a patient moves practice, all their ACP information held in the previous Practice’s GP IT System should be transferred to the new practice. This functionality will be partially automated via delivery of the ‘GP2GP’ solution’s transfer process.
• Sharing of ACP content beyond NHSScotland is rarely done, and is likely to be done using a letter, or by the patient.

**Legislation and Binding content**

Most H&SCProfs understand the content of an ACP to be the patient’s preferences, and that these are not legally binding. Each scenario requires professional judgement. As an example, Paramedics need to exercise distinctly unique judgement in determining whether DNA CPR is inappropriate for a patient’s current situation when it is deemed to be unrelated to their long term condition.

Some people suggested that the content is potentially morally binding, and all agreed that, where practically possible, a patient’s preferences should always be followed.

The Mental Health Act stipulates that patients must be treated with much greater rigour with respect to their Advance Statements. The Mental Health Tribunal process has greater power to call clinicians to account to justify any variation between the Advance Statement and care that was provided.
Who owns the ACP?
The impression given by many but not all GPs is that GPs have the sole responsibility of entering the ACP, therefore they hold ownership of the content. The alternative perspective is considerably different. While some believe the status quo is adequate, other feedback about expanding ownership has two themes.

One theme is to expand the ownership of ACP content by opening GP systems for other disciplines to create and update ACPs, potentially every type of H&SCProf including District Nurses, Community Pharmacists, Secondary Care Consultants and Junior Doctors, etc. The other theme is based on the opinion that GPs should not be entering ACP content at all since they see the ACP content as being entirely derived by the patient.

There is a perception that the Consent model relating to ECS and KIS can be confusing both for users of the GP IT Systems and those outwith GP practices who have "read-access".

On the premise that people can take responsibility and control of their own information, it was felt by many contributors that ACP content should be managed by the person, not the H&SCProf. There is precedence in this regard with Midwifery, where pregnant women hold their own clinical record throughout their pregnancy and beyond.

The afore-mentioned development of a ‘myACP’ app could give informed individuals full ownership of their ACP content\(^{29}\), enabling them to provide consent for H&SCProfs and others such as friends and family to access their information. The understandable need for H&SCProfs to access ACP information in emergency and EOL situations indicates that ACP information should be stored centrally and made available to other systems in a similar way to ECS\(^ {30}\).

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\(^{29}\) Concern was noted that an ACP app would likely increase the deprivation gap between those with mobile devices and patients in highly deprived areas.

\(^{30}\) Patients requiring emergency treatment may not be in a suitable position to provide emergency staff with access to their ACP content if the information is solely held on a mobile device.
Challenging Conflations

Firstly, it is difficult for GPs and many other H&SCProfs to disassociate between various elements. The terminology issue discussed earlier is one significant contributor of ambiguity, as elements of ACP, KIS, ECS and ePCS, can be incorrectly used interchangeably. Another potential cause is the duplication of information within the GP IT Systems as some ACP content can be held twice in the same system. This is pertinent to those who can access the full patient record from ECS and KIS, especially where two parts conflict. These occurrences lower data quality, which consequentially leads to uncertainty among users. On a similar theme, a reference to ACP is assumed by some to be the paper form, while others assume it is the electronic content held within KIS.

Secondly, there is no separation in how personal ACP content and clinical ACP content are captured, shared, and maintained. This leads to operational ambiguity across disciplines, especially for those who have view access to the full ECS record outwith the Practice. Typically, creators and readers of ACPs across Primary and Secondary Care understand the ACP to be an indication of the patient’s preferences in the context of what may be clinically possible. However, Community workers understand the ACP to be entirely the patient’s wishes, where the patient retains full control of the ACP content at all times, and has the option of adding appropriate clinical content for reference only, for example, noting recent hospital admissions and any relevant advice from H&SCProfs.

Thirdly, although an Anticipatory Care Plan is distinctly different to the Anticipatory Care Planning process, many references to each are used synonymously and ambiguously. Clearer distinction between the two, and greater awareness of the distinction, would raise the importance of the conversation between the two experts, the patient and the H&SCProfs, as well as the importance of the information captured.
Areas for potential improvement

Blank ACP / KIS
The content entered by a GP is critically important for other parties to exercise effective use. In the course of discussions, a number of poor operational procedures have been highlighted.

One common example is where some GP records have been marked as having a KIS, but the content has been left blank in preparation for meeting with the patient at a later date and obtaining their consent. When non practice based staff (for example, Acute, SAS or NHS24) review these patients’ records via ECS, it appears that each of these patients should have some ACP or KIS content but the information viewed is blank. This has led to a mistrust of the IT systems and interfaces even though these are working correctly. In an Acute setting with staff under significant time pressure, this issue reduces the likelihood of staff viewing ACP and KIS information via ECS in future.

GP flag setting
In addition to Patient Consent being required unless overruled, the KIS record in the GP IT system can be set to disable the uploading to ECS. This is likely used by GPs as a temporary ‘completion’ status marker during the conversation with the patient, but introduces the risk of this status remaining indefinitely. Affected KIS records will therefore not be uploaded from GP IT system to ECS, and will not be accessible to any other receiving system.

Expired ACP / KIS information
One of the key features of KIS is the presence of the Special Note. This allows a sometimes lengthy clinical note to be recorded and shared within a patient’s KIS record. The KIS requirements specify that this note must be merged with the equivalent ePCS field which is ‘Additional Useul OOH Information’. The most recent content from the ACP and Special Notes field is brought together in the KIS record. The key difference is that the ‘Special Note’ contains an expiry date as often the content is only relevant within a particular time frame. Upon expiry, a replacement blank note is sent but the other contents of the KIS remains. The GP system keeps the note after expiry.

While most practices do not set an Expiry Date for this reason, the impact of setting an Expiry Date unnecessarily results in NHS24 and SAS staff seeing that a patient has a KIS record in ECS but the content cannot be viewed.

Misuse of ACP forms
Although a patient may take the trouble to bring their ACP document to hospital, the form can routinely be ‘kept safe’ by being placed with the patient’s belongings during the patient’s stay, therefore not available to be used to support patient’s wishes.
Information Sharing Proposals
Contributors’ suggestions are documented here at a high-level, and are formed as proposals for consideration. Detailed gathering of functional and non-functional requirements is not an expectation from this report.

Although a question has been voiced about searching for an ‘unnecessary grail’, some things can be done to improve ACP information sharing.

These proposals are intended to stimulate discussion on how the accessibility of ACP content can be improved across all technical, political, governance, operational, and geographical boundaries. Given the diversity of contributors, some proposals contend with others, and can potentially be mutually exclusive.

Table of proposals and areas of potential impact:

<table>
<thead>
<tr>
<th>Proposal description</th>
<th>Technical</th>
<th>Political</th>
<th>Governance</th>
<th>Operational</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Provide access to ACP information for all relevant parties who provide health or</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>social care (e.g. NHS, Social Care, Hospices, Nursing / Residential Care Homes, and</td>
<td></td>
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<tr>
<td>recognised Voluntary Sector organisations)</td>
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</tr>
<tr>
<td>2. Provide access to ACP information for all parties whether ‘clinical’ or not</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>3. Ensure GP IT Systems can capture all required ACP information appropriately</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Ensure GP IT Systems can capture more ACP information (current size limitation</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
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<tr>
<td>inhibits content)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>5. Build new interfaces with Private or Third Sector e.g. to Marie Curie; CHASCare</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>6. Provide Advance Statements to front-line staff in the same way as ACPs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>7. Build electronic textual import of coded (e.g. READ(^{\text{31}}) / ICD10 / SNOMED</td>
<td>Y</td>
<td>Y</td>
<td></td>
<td></td>
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<tr>
<td>CT) diagnoses, updating as ECS does</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>8. Build opt-out for patients: whole record or part of their record.</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>9. Increase use of data transfer and linkage between SAS Ambulances and hospital</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>systems to widen access to ACP information</td>
<td></td>
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</tbody>
</table>

\(^{31}\) The READ Coding system provided updates until March 2016
<p>| | | | | |</p>
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</thead>
<tbody>
<tr>
<td>10.</td>
<td>Provide education in advanced communication skills for teams having conversations with patients</td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Raise awareness of ACPs among less senior staff</td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>Ensure adequate time for H&amp;SC professionals to be with people to work through what they want</td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Ensure ACPs (paper or electronic) are shareable</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>14.</td>
<td>Provide guidance on use of ACP content and circumstances in which the ACP applies (e.g. the difference between an emergency situation and a Long Term Condition)</td>
<td></td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Ensure IT systems, processes and integration can facilitate the “House of Care” model for capturing the discussions between the two experts</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>16.</td>
<td>Ensure a wider common understanding of who owns ACP information (i.e. the Patient or NHSScotland or GPs) taking into consideration relevant IG aspects</td>
<td>Y</td>
<td>Y</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>Enable patients to enter their own ACP information</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>18.</td>
<td>Enable patients to decide who can view and update their ACP information</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>19.</td>
<td>Consider development of a ‘myAdvanceStatement’ system, with information accessible by H&amp;SCProfs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>20.</td>
<td>Open up GP IT systems for read access by all H&amp;SCProfs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>21.</td>
<td>Open up GP IT systems for update access by all H&amp;SCProfs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>22.</td>
<td>Consider the creation of an alternative ACP information store (separate to GP IT Systems), with read and update access by all patients and H&amp;SCProfs</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
<tr>
<td>23.</td>
<td>Consider building an acknowledgement step for GPs to confirm updates from external parties have been completed in GP IT Systems</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24.</td>
<td>Increase user awareness with a clearer distinction of the elements of ACP i.e. Clinical v Personal information</td>
<td>Y</td>
<td></td>
<td></td>
</tr>
<tr>
<td>25.</td>
<td>Consider inclusion of MHAS content into a KIS for a patient (with consent)</td>
<td>Y</td>
<td>Y</td>
<td>Y</td>
</tr>
</tbody>
</table>
## Glossary of Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
<th>Further Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP (planning)</td>
<td>Anticipatory Care Planning</td>
<td>This is the process of discussion (the conversation) between the person and the H&amp;SCProf to determine the person’s wishes</td>
</tr>
<tr>
<td>ACP (the Plan)</td>
<td>Anticipatory Care Plan</td>
<td>The ACP content comes from the Planning process and the information is typically entered into the GP IT system, and/or written in a document held by a patient. An ACP is different from an ‘Advance Care Plan’</td>
</tr>
<tr>
<td>eACP</td>
<td>electronic Anticipatory Care Plans</td>
<td>This refers to the electronic Plans held within KIS32</td>
</tr>
<tr>
<td>AHP</td>
<td>Allied Health Professionals</td>
<td>A variety of disciplines (~12); some are employed by Health Boards, others by Councils</td>
</tr>
<tr>
<td>CAMHS</td>
<td>Child &amp; Adolescent Mental Health Services</td>
<td>i. A general description of this part of Mental Health services</td>
</tr>
<tr>
<td>Community First Responders</td>
<td>Community First Responders, SAS</td>
<td>ii. Also a national information system</td>
</tr>
<tr>
<td>COPD</td>
<td>Chronic Obstructive Pulmonary Disease</td>
<td></td>
</tr>
<tr>
<td>CYPACP</td>
<td>Children and Young Persons’ Advance Care Plan</td>
<td>Template form</td>
</tr>
<tr>
<td>CYPADM</td>
<td>Children and Young Persons Acute Deterioration Management</td>
<td>A plan containing patient preferences, including resuscitation</td>
</tr>
<tr>
<td>ECS</td>
<td>Emergency Care Summary</td>
<td>National system receiving a dataset of information from GP IT systems</td>
</tr>
<tr>
<td>ECTP</td>
<td>Emergency Care &amp; Treatment Plan</td>
<td>Paper document (currently draft) created by pan UK working group – renamed to ReSPECT</td>
</tr>
<tr>
<td>EOL</td>
<td>End of Life</td>
<td></td>
</tr>
<tr>
<td>ePCS</td>
<td>electronic Palliative Care Summary</td>
<td>A component of ECS</td>
</tr>
<tr>
<td>GP OOH</td>
<td>GP Out of Hours</td>
<td></td>
</tr>
<tr>
<td>HIS</td>
<td>Healthcare Improvement Scotland</td>
<td>A ‘Special’ Board within NHS Scotland</td>
</tr>
<tr>
<td>HKIS</td>
<td>Hospital KIS</td>
<td>Used in some hospitals</td>
</tr>
<tr>
<td>HoC</td>
<td>House of Care</td>
<td>Scottish Government’s new model of care</td>
</tr>
<tr>
<td>H&amp;SCProf</td>
<td>Health &amp; Social Care Professional</td>
<td>All sectors and disciplines</td>
</tr>
<tr>
<td>IDL</td>
<td>Intermediate Discharge Letter</td>
<td>Issued by Secondary Care for update in GP IT System</td>
</tr>
</tbody>
</table>

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32 http://www.ecs.scot.nhs.uk/kis
<table>
<thead>
<tr>
<th><strong>KIS</strong></th>
<th><strong>LWIC</strong></th>
<th><strong>ACP Commission, NSS IT</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Key Information Summary</strong></td>
<td><strong>Living Well In Communities</strong></td>
<td><strong>Part of the GP IT System, uploaded to ECS</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>Improvement work undertaken by H.I.S aligned to the 2020 vision</strong></td>
</tr>
<tr>
<td><strong>MHAS</strong></td>
<td><strong>Mental Health Advance</strong></td>
<td><strong>A statutory document under the Mental Health Act</strong></td>
</tr>
<tr>
<td><strong>Statement</strong></td>
<td><strong>’My Thinking Ahead, My Making Plans’</strong></td>
<td><strong>An ACP equivalent document used in some Health Boards</strong></td>
</tr>
<tr>
<td><strong>MTAMMP</strong></td>
<td></td>
<td><strong>An NHS non-territorial ‘special’ Board</strong></td>
</tr>
<tr>
<td></td>
<td><strong>‘My Thinking Ahead, My Making Plans’</strong></td>
<td><strong>A Strategic Business Unit of NSS</strong></td>
</tr>
<tr>
<td><strong>NHS24</strong></td>
<td></td>
<td><strong>A part of the ‘University of the West of Scotland’</strong></td>
</tr>
<tr>
<td></td>
<td><strong>NHS Scotland’s 24x7 health helpline</strong></td>
<td><strong>A national NHSScotland system identifying highest risk patients</strong></td>
</tr>
<tr>
<td></td>
<td><strong>National Services Scotland</strong></td>
<td><strong>An SG advisory group across all sectors</strong></td>
</tr>
<tr>
<td></td>
<td><strong>NSS IT</strong></td>
<td><strong>A pan NHS-UK collaborative form (not yet finalised – May 2016)</strong></td>
</tr>
<tr>
<td></td>
<td><strong>National Services Scotland</strong></td>
<td><strong>A document used to record an issue and what should be done</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>A part of the ‘University of the West of Scotland’</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Scottish Centre for Enabling Technologies</strong></td>
<td><strong>A National NHS Scotland System identifying highest risk patients</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Scottish Patients At Risk of Readmission or Admission</strong></td>
<td><strong>A Strategic Business Unit of NSS</strong></td>
</tr>
<tr>
<td></td>
<td><strong>Scottish Patients At Risk of Readmission or Admission</strong></td>
<td><strong>A Strategic Business Unit of NSS</strong></td>
</tr>
<tr>
<td></td>
<td></td>
<td><strong>An SG advisory group across all sectors</strong></td>
</tr>
</tbody>
</table>
Anticipatory Care Plans/Urgent Care Plans

A proactive approach to anticipatory care and case management can reduce avoidable admissions. Primary care and community teams should combine to identify those at greatest risk of avoidable admission to hospital, and ensure that a proactive approach is adopted to reduce the risks of exacerbations of illness, and to prepare effective support should deterioration develop.

Future development of electronic patient information summaries (building on the experience of the current Key Information Summary) should be based around Anticipatory Care Plans to enable a coordinated, person-centred approach across the health service.

(Eddie Turnbull, Head of Scottish Government eHealth - March 2016)

Eddie Turnbull also displayed this graphic to demonstrate that “2% of the population accounted for 50% of the hospital & GP prescribing expenditure” and use 77% of bed days (90% are unplanned). The LWIC HIS team are considering the ACP approach for a target of 5-6% of population. Focussed patient selection through SPARRA will help GPs achieve this.

One GP’s response to the potential reduction in hospital admissions is that it would increase demands on an already-burdened Primary Care, particularly since 25% of GPs are aged over 55 and many GPs are likely to retire over the next few years. While it might be less costly not to attend hospital, Primary Care would not cope with increasing demand.

33 Some practices use the “Supportive & Palliative Care Indicators Tool” (SPICT™) [http://www.spict.org.uk/](http://www.spict.org.uk/)
Scotland’s House of Care model

‘Gaun Yersel’, the Self Management Strategy for Long Term Conditions in Scotland was launched by The ALLIANCE and the Scottish Government in September 2008, where it marked a significant shift towards self management. The strategy had two principles of engagement:

- “The partnership with the individual is central to the self management agenda”
- “I am the leading partner in the management of my own health”

However, there is a sense that the ‘patient-centred-care’ focus gives the impression that care is being done ‘TO’ people, thereby significantly reducing patient engagement.

The House of Care (HoC) is a new model of care that has been developing over recent years as a progression from ‘Patient-Centred Care’. The two models differ subtly yet distinctly in where the patient is placed.

HoC moves to a more collaborative approach where the patient is treated as an expert in their own care, and the H&SCProf is another expert in the patient’s care. This model centres around the conversation these two experts have on a particular issue to ensure that the most appropriate Care & Support Planning – and therefore the most appropriate Care & Support Plan - is agreed.

This model is developing momentum and wider coverage across the H&SC agenda.

Another recent initiative to NHS Scotland, “What Matters To You”, originated in Norway in 2014. It has the similar aim of “encouraging and supporting more meaningful conversations between people who provide health and social care and the people, families and carers who receive health and social care”.

35 [http://www.whatmatterstoyou.scot/](http://www.whatmatterstoyou.scot/)
**Contributing Individuals and Acknowledgements**

Around 20 principal consultations and various additional communications were the main contributing sources for this report. Other professionals from various disciplines contributed, including those from the ACP Focus Groups. Zahid Deen, eHealth Strategic Lead for ‘The Alliance’, was informed of this work at an early stage.

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Role(s) / Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paul Adams</td>
<td>IJB; Glasgow City HSCP</td>
<td>Lead for ACPlanning, Head of Older People &amp; Primary Care Services, Glasgow City HSCP</td>
</tr>
<tr>
<td>Susan Kelso</td>
<td>Joint Improvement Team (JIT)</td>
<td>National AHP Clinical Lead and AHP ACP lead, Joint Improvement Team</td>
</tr>
<tr>
<td>Mark Fleming</td>
<td>NHS A&amp;A; Scottish Government</td>
<td>Mental Health Services Programme Manager, NHS A&amp;A eHealth; SG eHealth clinical adviser for NMAHPS</td>
</tr>
<tr>
<td>Mark Macgregor</td>
<td>NHS A&amp;A</td>
<td>Consultant Renal Physician and AMD</td>
</tr>
<tr>
<td>Daniel Beckett</td>
<td>NHS Forth Valley</td>
<td>Consultant in Acute Medicine, Hospital Front Door; Unscheduled Care Collaborative; “Managing Deteriorating Patient” guidelines.</td>
</tr>
<tr>
<td>Carole Smith</td>
<td>NHS Forth Valley</td>
<td>Lead Community Pharmacist; FVRH Community Pharmacist &amp; FV CP Champion</td>
</tr>
<tr>
<td>Fiona Stewart</td>
<td>NHS Forth Valley</td>
<td>ACP Nurses team lead, Stirling &amp; Clacks</td>
</tr>
<tr>
<td>Sandra Campbell</td>
<td>NHS Forth Valley</td>
<td>Macmillian Nurse Consultant for Cancer &amp; Palliative Care; PEOLCNAG contributor</td>
</tr>
<tr>
<td>Paul Baughan</td>
<td>NHS Forth Valley</td>
<td>GP Partner; Lead Cancer GP; PEOLCNAG member; Clinical Lead for roll out of KIS.</td>
</tr>
<tr>
<td>Euan Patterson</td>
<td>NHS GG&amp;C</td>
<td>GP; previously represented Palliative Care on the ECS service Board</td>
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<td>NHS GG&amp;C and CHAS</td>
<td>Diana Children’s Nurse (West of Scotland), Children’s Hospice Association Scotland. Currently leading a six month pilot to increase ACP usage in GG&amp;C</td>
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<td>NHS Highland</td>
<td>Consultant Physician. care of elderly physician</td>
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<td>Juliet Spiller</td>
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<td>Ian Thompson</td>
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<td>NHS24</td>
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</tr>
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Report on Anticipatory Care Planning
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ACP Commission, NSS IT  Page 28 of 28  15/09/2016
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</tr>
<tr>
<td><strong>Date Published/Issued</strong></td>
<td>19 April 2017</td>
</tr>
<tr>
<td><strong>Version/Issue Number</strong></td>
<td>V1.00</td>
</tr>
<tr>
<td><strong>Document Type</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Document Status</strong></td>
<td>External Review</td>
</tr>
<tr>
<td><strong>Author</strong></td>
<td>NSS IT Architecture &amp; Consulting</td>
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<tr>
<td><strong>Owners</strong></td>
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<td>Jan-Feb 2017</td>
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<tr>
<td>Feb 2017</td>
<td>Initial review from Stuart Cumming, KIS Commission Oversight Group</td>
<td>draft 0.09</td>
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<tr>
<td>Mar-Apr 2017</td>
<td>Additional content and internal reviews</td>
<td>draft 0.14</td>
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## Approvals: This document requires the following signed approvals.

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*Using this document:* All underlined text contain links to external content (URLs) or to sections within this document. Bold text may be occasionally used for additional emphasis, particularly for comparison of similar themes or things.
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1 Executive summary

Patient care is enhanced where pertinent information is shared and accessible by clinicians, and compromised where information is unavailable to those who have the responsibility of patient care.

The GP IT systems that are used by each GP in each Practice throughout NHS Scotland contain information that is very useful for the proficient and excellent care of Scotland’s citizens. This commission on the Key Information Summary (KIS) seeks to identify the extent of how the KIS part of the GP record is currently used throughout NHS Scotland and through the wider integration of Health and Social Care.

Although the pace of change of NHS technology often appears unbearably slow to some people, there are a number of improvements happening across Secondary Care to enable better sharing of information.

It is recognised that a relatively small number of individuals use the majority of our current healthcare resource. The initial target for KIS creation was 1.5% of patients on each Practice List. This target was linked to Quality Outcomes Framework (QOF) from 2014 to support the management of patients with complex needs. The focus was on the quantitative assessment of patients with KIS content rather than qualitative evaluation of the value added from KIS information.

All users of KIS agree that KIS is generally perceived and appreciated as a huge success. The KIS, through national ECS, has made information more readily available, and the information held in the KIS does assist in reducing admissions to Accident & Emergency and Acute Receiving Units. However, there is current and comprehensive consensus that KIS information is underutilised, and the variation of access to KIS information across NHS Boards is considerable. An expanded, cohesive and unified provision of KIS is one potential area that could be radically improved to enable consistent access across NHS Scotland for Secondary Care clinicians and care staff working in Health & Social Care Partnerships (HSCPs).

Until then, there is a desire to broaden the reach of the KIS by providing appropriate access to key disciplines where timely access to relevant and accurate information can make a difference to the health of the people of Scotland.

While this report makes no specific mention of the new European Union’s General Data Protection Regulation1 (EU GDPR), it is anticipated that these new regulations will significantly affect NHS information governance protocols. Further detail is being developed by the UK Government, which will be followed by guidance from the ICO. While this will bring clarification on the specific impacts to NHS system, it is understood that the ECS consent model currently fails to comply. These regulations have been incorporated into law, and come into effect on 25th May 2018, which is prior to the UK leaving the EU. The regulations are expected to apply to UK thereafter.

Contributions to this report have been received from most NHS Boards (through meetings and conversations with individuals and / or groups spanning a variety of disciplines). These contributions often i. provided information that appeared anecdotal and subjective rather than conclusive; ii. contained typical conflation of KIS, ECS and the electronic Palliative Care Summary (ePCS); and iii. consistently demonstrated the inconsistencies regarding how different people understand ECS and KIS, the various related consent models; and how things are done across Scotland.

---

1 General Data Protection Regulation (GDPR) (Regulation (EU) 2016/679). “The EU General Data Protection Regulation (GDPR) replaces the Data Protection Directive 95/46/EC and was designed to harmonize data privacy laws across Europe, to protect and empower all EU citizens data privacy and to reshape the way organizations across the region approach data privacy.” (extract taken from http://www.eugdpr.org/)
# Introduction

## 2.1 Document Purpose

This document is the National Services Scotland Information Technology (NSS IT) deliverable following an investigation into the current and potential use of the Key Information Summary component of the national Emergency Care Summary (ECS) system.

## 2.2 Background

This work is commissioned by the Scottish Government eHealth Directorate, and was defined by the Commission Response.

## 2.3 References


## 2.4 Intended Audience

- KIS Commission Oversight Group
- ECS Service Board
- ACP / KIS Advisory Group

## 2.5 Structure and Content

This report is structured in a way that presents the main themes and ideas that have arisen from the feedback, with additional detail being provided in appendices. This report is structured as follows:-

- **Chapter 1**: Executive summary - Provides a high level summary of the key areas of the KIS report
- **Chapter 2**: Introduction - Introduces the commission, provides some background, and gives the purpose and structure of the document
- **Chapter 3**: Overview of KIS - Describes a KIS record
- **Chapter 4**: Current use of KIS – Describes how KIS is populated and accessed
- **Chapter 5**: Better use of KIS – Describes additional use of KIS to support patient care
- **Chapter 6**: Considerations and Risks – Describes some of the key issues
- **Chapter 7**: Suggestions for improved use of KIS – Presents the many suggestions provided by the contributors
- **Chapter 8**: Conclusions - Recommends the next potential steps
- **Appendices** – various appendices contain a Glossary of Terms, and describe additional aspects of KIS at a more detailed level, bringing additional context to the findings and conclusions

The main body of this report can be read independently from the Appendices, with individual readers making reference to a particular Appendix of interest where required.
3 Overview of KIS

The KIS is part of the national ECS system and is a set of information taken from the GP IT systems along with ECS and ePCS information. These three parts (ECS, ePCS, KIS) are stored in one record for each patient, although the KIS content is only extracted from the GP IT system if the patient’s record has been marked as ‘Consent Given’ or consent has been overridden by the GP in specific circumstances to ensure relevant information is shared.

ECS and KIS were initially designed for Emergency and Unscheduled Care but are now also reported to be useful for routine care.

The general consensus of opinion indicates that the KIS provides a useful summary of a patient’s situation or their need to be treated in a particular way, but KIS readers\(^2\) note that at times “there is too much written and not enough done”, and “the more you add, the less you see”.

Some clinicians would describe themselves as avid KIS readers because they understand the benefit to their patients and themselves. Even so, across the entire clinical community, there is still a low level of KIS awareness, and of those who are aware, there remains a low level of understanding of the purpose and content of a KIS. One important observation noted is that KIS is under used for a number of reasons, which are expanded upon later in this report. Some clinicians require clarification on what a KIS is since they use it so infrequently. When speaking with clinicians, patients often don’t remember information that can be helpful for their care hence some clinicians see the “Visibility of KIS as critical”. Clinicians also note that they find it useful to know ‘non-clinical’ content from KIS such as disability or accessibility information.

KIS information is maintained by GP Practices. New information can arise from direct interaction between the GP and the patient, or through the processes of transferring information from Secondary Care to the patient’s Practice. Some of these processes are discussed below.

\(^2\) People who use the content of KIS can be described as ‘KIS readers’ or ‘KIS consumers’
4 Current use of KIS

When the KIS dataset was added to the national ECS system, users accessed this information by means of an individual account for logging in to the ECS Web site. With the introduction of ECS Web Services, widely used Patient Management Systems (PMS) or Clinical Portals had the potential to provision seamless access for staff groups with little administrative burden compared with the requirement to create individual ECS accounts for each user.

The most common way for NHS Boards to access KIS is still via the ECS web site; however some Boards have changed their default method of accessing ECS from browser access to accessing via their Clinical Portal or their PMS. The fact that many of the larger Boards access ECS through their Clinical Portal means that the number of accesses using ECS Web Services now supersedes the number of accesses through the ECS website\(^3\).

Table A: The typical method of accessing ECS / KIS information by NHS Board:

<table>
<thead>
<tr>
<th>NHS Board</th>
<th>Web URL</th>
<th>Clinical Portal</th>
<th>PMS / TrakCare</th>
<th>Other (e.g. local system)</th>
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<tr>
<td>Ayrshire &amp; Arran</td>
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<td>✔️</td>
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<tr>
<td>Borders</td>
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<td>✔️ (URL)</td>
<td>✔️ (URL)</td>
<td>✔️</td>
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<td>Dumfries &amp; Galloway</td>
<td>✔️</td>
<td>✔️</td>
<td></td>
<td></td>
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<tr>
<td>Fife</td>
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<td>✔️</td>
<td></td>
<td></td>
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<td>Grampian</td>
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<td>SAS</td>
<td>✔️</td>
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<tr>
<td>FMS (NHS Forensic Medical Services)</td>
<td>✔️ (some use Adastra)</td>
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All TrakCare implementations, except NHS Lothian and some Clinical Portals, redirect users to the ECS web system where they are required to login.

In addition to NHS Board Secondary Care staff, other services (such as GP Out of Hours, and some NHS Forensic Medical Services - FMS) access ECS / KIS via Adastra; other Health & Social Care Professionals (H&SCProfs) have access through the local PMS or Clinical Portals. For example, Marie Curie Hospice in Edinburgh (palliative consultants, medical team, Admin\(^4\), and community / specialist nurses) access ECS / KIS through NHS Lothian’s TrakCare and / or Clinical Portal\(^5\).

Generally, the provision of KIS information via ECS is considered by KIS readers to be good, despite some issues, as it provides more efficient and safer provision of information for patient care than prior to it being available. Many clinicians say that Clinical Portal access to KIS is very good,

\(^3\) 75% of accesses are through Web Services; 25% is Web system based access (logging via the ECS URL)

\(^4\) Admin access Clinic Letters for printing of Death Certificates.

\(^5\) Marie Curie Hospice (Edinburgh & Glasgow) are moving to the EMIS based platform in 2-3 years, which enables linkage between EMIS practices. This will provide easier access to patient info directly from the GP IT systems (EMIS only).
and particularly valuable where it includes access to their patients’ information from another NHS Board.

One or more Boards provide access to ECS / KIS via multiple routes, for example, directly via the Web System, via Clinical Portal or PMS, via Adastra, and / or via an A&E system. The unavailability of a Board’s Clinical Portal poses a potentially significant challenge, since affected users use their ECS passwords so infrequently that they would need to be reset using processes that may have since become redundant.

Non-NHS staff may receive pertinent KIS information directly from NHS staff verbally, for example, at Multidisciplinary Team Meetings (MDTs), or the wider Multi Agency Triage Team meetings (MATTs), or during Out of Hours (OOH) handovers between NHS and Social Care, or from NHS staff working closely with other agencies such as the Police or the Scottish Prison Service (SPS).

One hospital Pharmacist considered that there is still little likelihood of KIS being of use by the majority of hospital Pharmacists.

The ‘free text’ Special Notes is the most useful KIS field to many clinicians.

Access to KIS is often constrained to Consultants, Hospital Doctors, or Hospital Pharmacists, and is rarely given to other staff such as Nurses and Allied Health Professionals (AHPs). Scotland-wide information acquired from eHealth Clinical Leads and other key representatives in each NHS Board is detailed in Appendix B.
5 Better use of KIS

There are a number of good examples around Scotland on how KIS is used. This section highlights examples of good practice, discusses some of the issues, and presents potential areas for improved use of KIS.

5.1 Ease of identifying when a KIS exists

While Medical staff are widely aware of ECS allowing access to medicines and allergies, there is a belief that other useful information contained in KIS could provide clinicians with enhanced patient information, however this is not widely publicised. The response from many NHS Scotland clinicians about how they know if a KIS exists is simply: “We don’t”, even though most or all of these people have ECS access. There is a similar response from clinicians where those working outwith NHS Board boundaries are blind to KIS content, for example in Palliative Care organisations, while those having dual roles may have an advantage of being able to access additional NHS systems concurrently.

Knowing a patient’s preferences and other key information can help reduce unnecessary hospital visits and misguided use of NHS resource. For example, where KIS information is either unavailable or unused, an uninjured faller would most likely be taken to A&E as it is much easier for a paramedic to admit (45 minutes) than to arrange for a patient to be taken back home (2-3 hours).

Examples of how KIS is accessed are provided in Appendix C.

Adastra users (OOH and FMS) find that it is very easy to see if a KIS exists as Adastra shows a ‘KIS Record Available’ message if a KIS exists, and users can also check the Special Notes content.

NHS24 are provided with a file several times each day, which identifies patients that have a KIS record. This information is uploaded to NHS24’s system (PRM) indicating that a KIS exists. NHS24 staff can then login to the ECS web system to review the record. However NHS24 does not receive an update when a KIS record expires, which causes staff to think that a KIS record is “missing”.

Although the ECS web system shows the KIS tab when a KIS exists, users who have no direct means of determining if a patient has a KIS, such as NHS24 and Scottish Ambulance Service (SAS) call handlers, must use other means such as logging in to ECS to find out whether a KIS exists or not.

NHS Tayside’s Clinical Portal shows a live tab when a patient has a KIS. NHS Lothian’s TrakCare is similar, where the KIS tab has been made more prominent and is now shown at the top of the screen if a KIS Report has been generated into a ‘puff’ file. However the absence of this KIS tab may mean that either no-one has generated the local KIS ‘pdf’, or that there is no KIS available to ECS.

Given that patients with KIS content have consented to all their ECS information being shared, NHS Forth Valley revised their Clinical Portal’s presentation of ECS and KIS content. KIS information is now displayed automatically whenever it exists, and consequently the need to ask for additional consent to access ECS information is removed. This resolves problems such as clinicians not knowing whether they are ‘allowed’ to access KIS content if the situation is not an emergency, or if the patient is not in attendance to provide access approval. Where a patient’s record does not show KIS content, the Forth Valley Clinical Portal prompts the user to select a reason for access to ensure appropriate consent has been given, which is in line with current consent guidelines.

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6 Most of these patients are elderly and are often not discharged unless to a Nursing Home.
7 PRM is NHS24’s current call management system
8 Generating a KIS report as a PDF file that is stored within TrakCare is functionality specific to NHS Lothian. This process can be performed at any time, ideally between admission and consultation.
These are example of local solutions that have been implemented to improve KIS awareness and accessibility. More examples are detailed in Appendix D, and additional comment on Patient Consent is contained in Appendix G.

5.2 Extended access to KIS

Many contributors thought it was important that patients themselves should be able to access their own records, and potentially control access to their own records.

In addition to the patients, disciplines such as Nurses and Community Pharmacists were common requests for specific staff roles to be given access. General feeling among all those who were consulted was that everyone involved in the care of patients should have access to the KIS.

While some NHS Boards have initiated local pilots to provide a small number of Community Pharmacists with access to ECS, the Scottish GP Committee (SGPC) and the Scottish Government (SG) have been working towards ensuring appropriate access to ECS/KIS can be provided across each NHS Board, subject to the appropriate governance being understood and followed by all groups and individuals.9

One senior clinician noted: “any health care agency in Scotland should be able to access” KIS information; and “with such a mobile population, it is imperative that patients can be treated appropriately”. The analogy was given that they (the clinician providing comment) should be able to access patient information as they can look up a patient’s Radiology image from anywhere else in Scotland. So it could be more effective and efficient if all involved with a patient’s care could access KIS, however in certain situations there are risks associated with misinterpretation of some of the KIS information by untrained staff.

Unless an NHS Board has developed the capability to view different information based on a user’s role, there is no ability to separate clinical and non-clinical content. The potential ‘risk of misinterpretation’ by call handlers in NHS24 / SAS means they have no access to KIS, therefore cannot easily access the useful non-clinical information such as Next Of Kin and OOH GP contacts; Clinical Supervisors access KIS content when a Call Handler requests further information.

The variety of AHP disciplines presents particular challenges, where one solution doesn’t fit all. Most AHPs are employed by NHS Boards while around 500 Occupational Therapists are employed by Local Authorities. Information Governance requirements will require some differentiation between Board employees and ‘external’ third party contractors, where Board employees are easier to accommodate.

Based on how each Board applies access policies, some teams and individuals do not have adequate access to KIS content, for example: Community Mental Health; Child Health; Community Nursing.

5.3 Closing the information flow loop

KIS content is created within a GP Practice, and all updates are only performed within the GP Practice. In general, the creation of a KIS does not help a GP with their responsibilities of patient care as ECS was intended for use in emergency care situations external to the practice. The flow of KIS content, originating from and returning to the GP IT System, is often incomplete since there is no ‘closed loop’ to ensure all necessary updates are applied to the KIS.

Where information is incomplete, clinicians in Secondary Care do not know the full picture, and information is made more complete when a Practice updates the Patients’ GP IT record promptly with new information from all relevant sources. Feeding information from secondary care back to primary care is normally done using routine methods of communication - Discharge Letters, Summaries, or Clinic Letters. However, there is a degree of inconsistency in media (electronic, telephone call, email, or paper), format and structure; therefore it is difficult to ensure relevant data is updated in a Patient’s record within their practice.

9 Forth Valley’s Clinical Portal is to be provisioned with a ‘Break Glass’ option for Band 5 Hospital nurses. This is to be switched on when the auditing process is fully available.
These communications are sent to, and stored by, the Practice, enabling GPs to access information readily, therefore there is rarely any concern for Primary Care who perceive that the “loop is closed well” since communications issued from Secondary Care to the General Practices are accessible within each Practice.

The information returning from secondary care normally requires manual reading and transcribing into the GP IT System, which is done by a GP or other Practice staff. Mention was made of Intermediate Discharge Letters (IDLs) previously being faxed or given to the patient, and that many of these are now issued to Practices electronically via DocMan.

One oncology Clinical Director noted that diagnoses are not entered into the GP IT systems for the vast majority of chemotherapy patients. The inability of ECS / KIS to assist with provision of relevant information will continue unless all GPs add relevant information to ensure inclusion of significant diagnoses.

Many users suggest it is difficult to feed information back to GPs because it is a one way flow, while recognising that this has both advantages and disadvantages. One Board’s clinicians are about to receive access to SWIS\(^\text{10}\), and are in discussion regarding the ability to feed some information back to Social Work. This model may have further potential for other Boards.

Some KIS users suggest that the discharge Letters sent to GPs are typically not updated, except for Medicine / Prescription changes. Such information, which normally goes to GPs for information but is not always captured within the GP IT systems, means that when a patient visits other hospitals, clinicians do not have full visibility unless the patient brings the information.

There are gaps in recording Secondary Care communications (for example, Discharge Letters) into the GP’s patient notes, and in compilation of the KIS from the GP’s patient notes. For example, when some GPs choose to copy certain codes across to a KIS, the codes tagged ‘significant’ and ‘past’ do not appear on their list, therefore any significant procedures in the past may be missed. Another GP noted that “the GP decides what information is updated in KIS / ACP. GPs would update procedures but not necessarily KIS content.” Some KIS information is not clinical such as Next Of Kin, and does not need to be on the GP system even though GPs are currently expected to maintain this information. The same GP suggested that a citizen record should hold this information, and the patient should have the control.

Where consent has been withheld either on ECS or at a Clinic such as Sexual Health, the flow of data may be broken in either direction\(^\text{11}\), therefore GPs would not know about a patient’s interactions with secondary care, and Clinicians would not know appropriate information from the patient’s KIS.

A number of methods are employed locally to attempt closure of the information loop with varying degrees of success. Without a fully closed loop system, the reliance on practice staff to complete the loop manually, with no immediate benefit to the practice, will always present a risk.

Significant improvements have been made with the flow of KIS and ECS information from Secondary to Primary Care in some NHS Boards. In both examples below, GPs appreciate the ease and improved efficiency of information processing. The first example already applies to KIS content, and the second refers to a clearer communication process giving increased accuracy of Medication changes, which is a process that could be adopted for communication of changes to KIS content.

Example 1:
Important information or changes to information are highlighted at the top of Discharge Letters to attract the GP’s attention.

Example 2:

\(^{10}\) SWIS is one of the main Social Work systems
\(^{11}\) GP Practice to Clinic and / or Clinic to GP Practice
Discharge Letters use four Medication categories listed: STOPPED; ALTERED; NEW; UNCHANGED.

The proposal to adapt the second example to KIS changes is worthy of special mention. The process to record changes to IDLs for Medicines was initiated through the Scottish Patient Safety Programme (SPSF) and introduced four sections for Medications: STOPPED, ALTERED, NEW, UNCHANGED. For KIS content, significant changes such as DNACPR could be highlighted using the ‘NEW’, ‘ALTERED’ and ‘STOPPED’ categories. Notification of all unchanged KIS information is likely to be redundant, and an ‘UNCHANGED’ category is unlikely to be beneficial. As discussed later in this report, GPs like this as it is clear, the categorisation is easy to decipher, information can be processed much easier than manual digestion, and relevant information is incorporated better into the GP IT record. GPs are consequently more likely to update the patient record in their GP IT system.

Due to the ease of use and increased safety, these methods, particularly the multi-part categorisation, could potentially be used for many other communications to GPs.

**NHS24** update General Practices via Adastra of additional care or new medicines being provided to patients that appear not to be already known by the Practice.\(^\text{12}\)

IDLs for patients being discharged from **NHS Golden Jubilee National Hospital** are sent manually to Practices in some Boards, while working through a change programme to issue via Electronic Document Transfer (EDT) to Practices within all Boards\(^\text{13}\). Communications are always sent to the Referring Consultant, and sometimes to the patient too.

The OOH service in some boards currently emails each practice throughout each evening. The following morning, each practice takes the emails into DocMan, and then relevant content from DocMan should be entered into the patient’s GP IT record, although this is thought to be done in some practices with little evaluation of content\(^\text{14}\). As a precaution, OOH always call the practice to discuss morning visits, and after any OOH deaths.

GP IT systems allow GPs to note that some medicines have been provided to the patient through other routes, for example, from hospital clinics or A&E. These may be recorded within the GP IT system as ‘outwith Practice’ or ‘Hospital’, however some medicines are classed in the BNF\(^\text{15}\) as ‘Hospital Use Only’ and therefore may not appear in the Practice’s Drug Dictionary, causing the GP IT record to be incomplete.

National organisations such as SAS and NHS24 have unique challenges passing patient information on to Boards due to the diversity of Board systems. Only the clinical records for patients who are not admitted to hospital are sent electronically from SAS to the patients’ GPs. SAS are confident that GPs read and value the information that is issued, although they are unsure how often or how well GPs update the patient record.

In **NHS Tayside**, the Vision GP Practice systems have a link to the Board’s Clinical Portal giving all GPs direct access to hospital content, therefore; paper-based information from Secondary Care is reducing; EDT sends to DocMan and Clinical Portal; and emails are discouraged. In **NHS GG&C**, some GPs have access to the GG&C Clinical Portal. In both of these Boards, GPs are able to view how KIS / ECS users are presented with Patient information from the GP IT system, and they can compare both Primary and Secondary Care information together. In some Boards, Electronic Discharge Letters (eDLs) are issued for most of the patients receiving palliative care. Discharge Letters are sent to DocMan where the GP can copy appropriate content into the GP IT record. Some Practices have “robust processes that include phoning the patients” to review content.

When there is a need for **Police Custody Scotland** to inform a GP, for example where the patient may have expressed suicidal thoughts, may not be taking medication, or is a risk to self or others, the doctor or nurse would call the practice the next morning as there is no

\(^{12}\) All NHS Boards can access NHSS4’s summaries that are sent to Adastra. NHSS4 do not resend ECS content.

\(^{13}\) GG&C, Lothian, and Lanarkshire are now receiving IDLs from GJNH via EDT, and other boards will follow.

\(^{14}\) A new OOH process is being implemented where emails will be sent to EDT. EDT will put the content directly into DocMan, but entry into GP IT system will still require manual process to include info from EDT.

\(^{15}\) BNF – the British National Formulary – is the nationally accepted standard directory containing available drugs
automated means of direct communication from Police Custody Scotland’s Adastra to the Practice.

**Community Nurses** visit patients discharged from hospices, which may initiate requests to the GP to update KIS / ECS. If it is noticed that information remains unchanged, the GP is reminded. Discharge letters from Marie Curie Hospice are emailed to GPs in Word and scanned format, so GPs are able to copy and paste content easily.

Social Care and other non-NHS staff would currently inform a GP at an MDT or would call the GP directly.

A number of suggestions were offered on how the feedback of KIS content to GPs could be improved (these are detailed later in this report).

### 5.4 Quality and relevance of information extracted into the KIS

Earlier adopters of KIS noted that there was poor data quality initially. The two most common responses received were either that “KIS quality is variable” or is “unknown”. Some suggested that the GP is the biggest variable, and that it is dependent on the right people understanding what is important and appropriate, therefore there can be significant variance. The existence of multiple variations of DNACPR statuses (for example DNACPR, DNAR, CPR) was also noted as a quality issue.

Some NHS Boards plan to undertake a quality review to evaluate KIS content. Recent feedback received noted that the quality is “probably improving” since i. “lots of information is typed therefore legible”, and ii. good eDLs and e-letters are issued from Out Patient clinics. One Clinician / GP stated that updates are “relatively reliable if clearly marked”.

One GP noted that KIS / ECS are “better than nothing even if the content isn’t 100% accurate” and it is “much improved from 10 years ago”, although another GP / clinician suggested that following the removal of ‘QOF’ in the new GMS contract, quality is lower now due to more free text being added by salaried GPs and Locums.

Some clinicians feel constrained in that they can neither ask nor tell a GP to include any specific information into the KIS because it is unclear to many clinicians whether GPs are contractually required to update their records with Secondary Care information. At present, changes cannot be mandated easily.

Any user of Forth Valley’s Clinical Portal can click a button to flag an inaccuracy (the ‘Report Data Quality’ function). This initiates an investigation to ensure data quality is continually improved.

One contributor noted that “as we move to patients having access to their own information, then it is important that the information is correct”. Another contributor noted that patient access should improve the quality of the data, but perhaps only if i. they had an easy way of reporting errors or amendments, and ii. the GPs responded.

Contributing factors to lower quality are:

1. The GP IT systems have three distinct places to enter information that should be added to the KIS i.e. the main patient record, the KIS, and the ePCS screen
2. Entering KIS updates, or creating an ACP within KIS, can sometimes take between 30 and 60 minutes
3. The lack of validation within the GP IT systems
4. The lack of feasibility checks within the GP IT systems
5. The lack of quality assurance of data in the GP IT systems
6. The lack of quality assurance of processes in the GP IT systems.
7. The lack of validation of KIS content when uploaded to ECS

While District or MacMillan nurses are unlikely to have adequate time to take over from GPs in creating KIS and ACP content, one GP suggested that the patients could do much of this work themselves noting that “We need to allow other people to gather information and share it. This would produce more data”.
5.5 Breaking the Read-Only barrier

Some people, including GPs, suggest that it is GPs who are least in need of viewing the content of a KIS, and some GPs would say that they are often not even the best people to create KIS content. Many health professionals - GPs, Hospital Clinicians (Consultants, Doctors, Nurses, Pharmacists), community Pharmacists, NMAHPs, and other disciplines are increasingly calling for the ability for Health Professionals to co-create KIS content. One GP stated the need for “a better system that doesn’t require the GPs”. A consultant oncologist / haematologist emphasised the need for a response to this “call for oncologists to be able to co-create the KIS by using the specialist nursing staff etc”, pointing out that “We have time to do this, which the GP may not do”, and noting that of all their “20 sick bone marrow / oncology patients, only one has a KIS.”

Consensus of opinion received suggests that “Read-Only isn’t enough” and that “People are asking why they can’t have access to update the patient / GP record.” As has already been discussed in this report, there is increasing amount of opinion arguing for patients to be able to access their own data, and even have control of the access to their data.
6  Considerations and Risks

6.1  Key Issues

Many of the key issues of KIS usage are centred around the awareness and accessibility of KIS, or the challenges in maintaining KIS content accurately.

- Lack of awareness by GPs of what data feeds KIS / ECS
- Many Secondary Care clinicians don’t know what a KIS is, or how to view KIS from their Board systems
- Difficulty for some users to easily tell if a KIS exists
- Many patients that would benefit from having a KIS do not yet have one
- Consent complexity causes clinicians confusion
- KIS content is not transferred when a patient transfers to another practice
- Some KIS records are inaccurate or incomplete
- Information returned to GPs for KIS update from Discharge Letters may not be updated promptly, accurately or completely. (For example, when NHS24 receive calls from recently discharged patients, particularly at the start of a weekend when information is unlikely to be updated until the next week.)
- Information is duplicated across GP IT fields. (For example, GPs are trained to add information from elsewhere in the GP IT system into the Special Notes field, but this field may not be kept updated; and content entered into ePCS and KIS can be ambiguous causing readers confusion)
- Users should be aware of known issues irrespective of whether they create or consume KIS content
- Potential misinterpretation of information by non clinical staff means call handlers in NHS24 / SAS are restricted from seeing useful parts of the KIS
- Limited ability to separate clinical and non-clinical content (for example call handlers in NHS24 / SAS cannot easily access some useful information such as Next Of Kin and OOH GP contacts due to ‘risk of misinterpretation’)
- The quality of KIS content is highly variable. ECS validation is switched off because of the high number of records failing to be uploaded due to poor data quality.
- There can be too much information in the KIS for it to be useful
- There can be too little information in the KIS for it to be useful
- Boards have different business rules for viewing and handling information; good practice guidelines; practice defaults. For example, filters to include or exclude GP IT information are applied locally at each Practice, which a GP can override for each patient. There is wide variation between users and practices.
- GPs / clinicians are concerned about Social Care not being able to access KIS

6.2  Considerations

While there are some technical issues with KIS and the way in which the IT systems that consume KIS data such as clinical portals and 3rd party applications in NHS24, OOH etc, there are other non-technical aspects that need consideration with extended use of KIS. GPs that input information into their GP IT system are not always aware of what populates the KIS record so understanding would need to be addressed before extending access to other disciplines. There are a number of well documented design and functionality issues being reviewed currently.
Attention would need to be given to guidance on how to use the information recorded in the KIS record as misinterpretation could cause clinical risk to the patient.

6.3 Risks
Retaining systems and processes as they are presents an ongoing risk of limited awareness and access.

Each potential solution, by default, will contain an element of risk, which should be assessed adequately before proceeding. Some key risks to be considered are noted below:

1. Risks in extending access to untrained staff versus the benefits
2. Risks in extending access while known issues require to be addressed (see Appendix F)
3. Overhead management for Boards of extending access

6.4 ECS Technical Analysis
NSS IT has been commissioned to undertake analysis of the technical issues with ECS. Details are provided in Appendix F.
7 Conclusions

Several Boards have tried to enhance the access and usability of KIS. Some of these endeavours have proven very worthwhile; others have added value by facilitating an increased understanding of the benefits, challenges and complexities inherent with shared use of national systems, particularly across Health and Social Care boundaries.

The following four sections are a summary of findings on the key areas that the KIS commission explored:

1. Current use of KIS and roll-out across Scotland

Although use of KIS has distinct challenges, the high value of KIS content is recognised by the clinician community. Generally, clinicians have full access to KIS although many do not access KIS content through limited awareness, and some ECS access procedures could be improved to enable easier access.

All contributors actively support the wider roll out of KIS to support patient care.

Patients assume clinicians can access all of their health information and are surprised when asked for consent. Consent confusion remains an inhibitor to easier access of relevant information.

2. Potential new users of KIS

All health professionals and workers with caring responsibility should have access to KIS content. This should include all other Health & Social Care staff, and Community Pharmacists in particular.

Patients should have access to their own health information.

3. Accessibility / information content issues

Access to KIS via Boards' PMS / Trak systems only presents a login to the ECS web system, rather than presenting KIS information to users directly on screen.

It is difficult for NHS24 to know for sure when a KIS exists.

A review is underway to identify and address functionality issues that exist within ECS and KIS.

Inconsistent access to KIS within Prisons as access is dependent on the Prison.

4. Solutions in place to assist KIS accessibility

NHS Forth Valley’s Clinical Portal prioritises presentation of KIS content for all patients with a KIS, and ECS content is shown without any requirement for additional consent from the patient.

Work by NHS Lothian continues to investigate and experiment with ways to increase awareness of KIS.

NHS Tayside and NHS GG&C provide ECS / KIS access to GPs via their Clinical Portal systems. This enables GPs to validate how their GP IT information has been assimilated into KIS content.

What next?

The efforts noted above should be encouraged and replicated throughout NHSScotland where possible. Awareness of KIS should be raised across the clinical communities.

Although there are many suggestions made for improving KIS use further, any chosen for further action will need to be assessed for merit and importance. Perhaps focus and encouragement should be given to expanding the existing successes. These less complex changes could have a significant impact in increasing the reach and usability of KIS content.
## 8 Appendices

### 8.1 Appendix A - Glossary of Terms, Definitions and Acronyms

<table>
<thead>
<tr>
<th>Term</th>
<th>Meaning</th>
<th>Further Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>ACP</td>
<td>Anticipatory Care Plan</td>
<td></td>
</tr>
<tr>
<td>AHP</td>
<td>Allied Health Professionals</td>
<td></td>
</tr>
<tr>
<td>Adastra</td>
<td>GP OOH system</td>
<td>Adastra collates information from all NHSScotland Practice GP IT Systems</td>
</tr>
<tr>
<td>CAMHS</td>
<td>Child &amp; Adolescent Mental Health Services / System</td>
<td>i. A general description of Mental Health services for children and adolescents ii. Also a national information system</td>
</tr>
<tr>
<td>CYPADM</td>
<td>Child or Young Persons Advance Deterioration Management</td>
<td></td>
</tr>
<tr>
<td>DNACPR</td>
<td>Resuscitation preference: “Do Not Attempt Cardio Pulmonary Resuscitation”</td>
<td>The KIS records the existence of a signed DNACPR form.</td>
</tr>
<tr>
<td>DocMan</td>
<td>IT system containing some patient documents</td>
<td>Documents issued from Secondary Care for GP Practices are sent to the Practice’s DocMan system</td>
</tr>
<tr>
<td>ECS</td>
<td>Emergency Care Summary system</td>
<td>The national system receiving a dataset of information from GP IT systems</td>
</tr>
<tr>
<td>eDL</td>
<td>Electronic Discharge Letters</td>
<td>Issued by Secondary Care to Primary Care Practices</td>
</tr>
<tr>
<td>EDT</td>
<td>Electronic Document Transfer</td>
<td>One of the systems that transfers information from one system to another</td>
</tr>
<tr>
<td>ePCS</td>
<td>electronic Palliative Care Summary</td>
<td>A component of ECS</td>
</tr>
<tr>
<td>FairWarning</td>
<td>FairWarning is a privacy breach detection software tool</td>
<td>FairWarning analyses system audit logs to identify potential inappropriate accesses - system users looking up records of colleagues, family members, neighbours or even their own records. In addition other unusual activities, users viewing large numbers of records over a relatively short period, logged in 24x7, etc., can also be identified</td>
</tr>
<tr>
<td>FMS</td>
<td>Forensic Medical Services</td>
<td></td>
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<tr>
<td>HSSCP</td>
<td>Health &amp; Social Care Partnership</td>
<td>Part of the NHS, working in Police Custody Suites</td>
</tr>
<tr>
<td>H&amp;SCProf</td>
<td>Health &amp; Social Care Professional</td>
<td>Includes professionals from all sectors and disciplines</td>
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<tr>
<td>HDL</td>
<td>Health Department Letter</td>
<td>A letter from Scottish Government to NHS Boards</td>
</tr>
<tr>
<td>IDL</td>
<td>Intermediate Discharge Letter</td>
<td>Issued by Secondary Care for GP awareness. Practices store these; GPs may update GP Systems</td>
</tr>
<tr>
<td>KIS</td>
<td>Key Information Summary</td>
<td>Information that is entered into the KIS component of the GP IT System and uploaded to ECS</td>
</tr>
<tr>
<td>NMAHP</td>
<td>Nursing, Midwifery and Allied Health Professions</td>
<td>This refers to all professions within these three categories</td>
</tr>
<tr>
<td>NSS</td>
<td>National Services Scotland</td>
<td>An NHS non-territorial ‘special’ Board</td>
</tr>
<tr>
<td>NSS IT</td>
<td>National Services Scotland Information Technology</td>
<td>A Strategic Business Unit of NSS</td>
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<tr>
<td>PMS</td>
<td>Patient Management System</td>
<td>The main administration system used across an NHS Board, such as TrakCare</td>
</tr>
<tr>
<td>SAS</td>
<td>Scottish Ambulance Service</td>
<td>An NHS non-territorial ‘special’ Board covering all areas of Scotland</td>
</tr>
<tr>
<td>SPSP</td>
<td>Scottish Patient Safety Programme</td>
<td>A national initiative to improve patient safety across Scotland</td>
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</tbody>
</table>
### 8.2 Appendix B - Current method of access to ECS/KIS

Table x: The typical method of Secondary Care staff accessing ECS / KIS information by Discipline and NHS Board:

<table>
<thead>
<tr>
<th>Discipline</th>
<th>NHS Board</th>
<th>Doctors</th>
<th>Pharmacist (Hospital)</th>
<th>Pharmacy Technician</th>
<th>Advanced Nurse Practitioner</th>
<th>Community Nurses</th>
<th>Other Nurses</th>
<th>AHPs</th>
<th>Health Care Assistant</th>
<th>MedRecs/Data Quality</th>
<th>Admin</th>
<th>eHealth</th>
<th>Legal</th>
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<tr>
<td>Ayrshire &amp; Arran</td>
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<td>Borders</td>
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<td>P/T</td>
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<td>GG&amp;C (RBAC)</td>
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<td>Golden Jubilee</td>
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<td>some</td>
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CP = Clinical Portal; P/T = PMS/Trak; URL = ECS Web based access via URL

These tables attempt to demonstrate significant variation across NHS Boards with both the processes to authorise KIS access, and the systems to provision KIS content. Some Boards provide more access by default; other boards heavily restrict access, with one or more boards withholding access to nurses “because they are not directly involved with the patient”. Local consultants are affected individually due to increased workload accessing KIS on behalf of other staff, and they are clear that the “current access is a major problem”, noting that “When the information provided was just Medicines, that was ok, but now with KIS and ACP, a lot more information is relevant. There is no risk with nurses having access”.

Some NHS Boards have polished processes such as Role Based Access Control groups for Clinical Portal; others are bureaucratic and burdensome, hindering effective patient care.

Caldicott Guardians and Information Governance Leads are involved with ensuring ECS access is audited. Further information on Access Auditing is detailed in Appendix F.
8.3 Appendix C - Examples of how KIS is accessed

1. Some NHS Boards have improved access to ECS and KIS by displaying the content directly into their PMS or their Clinical Portal.
2. TrakCare, the most widely used PMS, was expected to deliver ECS / KIS information via Web Services but in most instances displays an ECS tab instead, which simply prompts users to login to the ECS Web system.
3. Where Clinical Portal systems display ECS content, an ECS staff ‘directory’ is used to determine whether ECS / KIS tabs are displayed for each user, and to enable authorised users to access the content without an additional login process. If a user isn’t in the group, they simply don’t see the content.
4. While Clinical Portal provides a far more advantageous access method over ECS web access, some issues with Clinical Portal have caused some NHS Boards to regress to ECS Web system access. This has reintroduced the slower and more cumbersome method of reading KIS information.
5. In NHS Lothian, where KIS has been used since early 2014 following the KIS rollout from 2013, normal practice is for a clinician to ‘generate a KIS Report’ for a patient. This may happen any time after the patient has been admitted and before the clinician sees the patient.
6. NHS Lothian is developing an automated solution to check KIS existence and flag the patient’s record as having a KIS.
7. During an emergency call, the Scottish Ambulance Service call handlers can refer to a trained clinician with access to KIS information. After an ambulance is dispatched, the KIS is pulled down from national ECS, enabling ECS/KIS content to be presented en route using tablets located in both the front and the rear of the ambulance.
8. NHS24: ECS accounts for access via the Web Interface will be used until the new Futures system replaces the PRM system. NHS24 use individual accounts for KIS content since their PRM system only enables access to the non-KIS content of ECS via the embedded web services call. KIS is only available via the ECS web system at present. The new Futures application provides embedded access using web services. KIS will be shown to all users with no separate access required. NHS24’s Interactive Voice Response (IVR) informs the caller that all information will be accessed. NHS24 often advise Out Of Hours GPs to view KIS information.
9. KIS content is useful to NHS Forensic Medical Services (FMS), however even a busy custody suite only sees approximately one patient with KIS content per month, and the KIS’ ACP content is very rare. Police Custody Suite patients often exhibit drug seeking behaviour or are a risk to others, therefore visibility of this information for FMS doctors and nurses is particularly important in order to ensure that these patients are not seen by only one person. FMS in Tayside can access NHS Tayside’s Clinical Portal, detailing information such as Appointments, Clinical Communications, PMH, hospital visits, and Test Results. Adastra is available in each Policy Custody Suite, which has a link to the ECS system.
10. The GP OOH Services provided by each NHS Board use Adastra, which has KIS and ECS information on every patient in every Practice within that Board, but no access to information on patients beyond that Board. NHS Boards often have agreements with bordering Boards to share ECS / KIS data. ECS and KIS can be accessed directly (i.e. not via Adastra) for any patient outwith that Board, which is seen as a very useful alternative in these situations. Emergency Receiving Units and Acute Receiving Units can also access KIS content via Adastra or via ECS as required.

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16 Futures is the new NHS24 patient call management system (go-live expected throughout 2017)
17 If a caller does want NHS24 to do access their data, they have an option to discontinue the call.
11. From an OOH Service perspective, ECS and KIS are always accessed for Home Visits therefore considered more important than for those patients who attend the Primary Care Emergency Centre in person. This KIS access is essential as patients tend to be extremely unwell, may be receiving Palliative Care, or may simply be housebound.

12. Some GPs use KIS for short term use, for example where a patient is likely to deteriorate over the weekend. The Special Notes’ Expiry Date is set on or just beyond the patient’s expected recovery time. While this provides some flexibility and clearer information prior to the Expiry Date, a serious consequence is that the Special Note and other clinical information is no longer available via national ECS. GPs who follow this practice are likely to be unaware of the impact. Conversely, some KIS content does not expire that should, such as mention of neutropenia.18

13. NHS Ayrshire & Arran works closely with Police for patient benefit, with Mental Health Nursing staff based within the Police station who can access patient information from ‘FACE’, NHS Ayrshire & Arran’s CAMHS, and other NHS systems. This means the appropriate Services can be directed to the person’s home rather than taking the person to hospital by default therefore unnecessary admissions can be prevented.

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18 Neutropenia - potential side effect following chemotherapy
### 8.4 Appendix D - Solutions in place locally to assist KIS accessibility

A number of local solutions have been investigated by NHS Boards to assist the accessibility of KIS. While most NHS Boards access KIS information via the ECS website, some of these solutions have been of interest to other Boards:

1. Access through Clinical Portal / Patient Management Systems rather than ECS Web has increased access to KIS information
2. Automatic presentation of KIS information within Clinical Portal (as in Forth Valley).
3. A KIS Alert is used in NHS Lothian’s TrakCare. Other TrakCare NHS Boards are interested in the KIS Alert concept but are potentially constrained due to their consortium’s change prioritisation processes and having a different contract arrangement to Lothian’s arrangement with the TrakCare supplier (InterSystems).
4. In addition to the automated KIS Alert, NHS Lothian also provide a manual ‘KIS Alert’ mechanism for “patients that should have a KIS” where text is added into a Trak Alert to raise awareness for other clinicians. Although not ideal, this acts as a temporary KIS.
5. NHS Lothian created a “KIS-friendly” document template to allow non-GPs to forward KIS information to GP Practices’ clinical e-mail accounts. This enables easier transfer of information that can then be placed directly on to KIS in the GP IT system. This is still in use in some areas but was deemed too cumbersome in others.
6. The Intermediate Discharge Letter (IDL) Summary from Lothian’s Trak has two new sections: “Changes for ACP” and “Suggestions for KIS”, which are used especially in the ‘Medicine for the Elderly’ wards. These summaries are emailed to the patient’s Practice. Two associated concerns are that there is sometimes too much text, and the Patient Consent may be unknown.
7. On a patient’s registration with another GP Practice, some KIS records are printed in full since KIS content is otherwise “lost” when a patient transfers to another practice.
8. Lothian tested a ‘FORCE’ function in A&E for a short period. Where a KIS existed, A&E users had to view the KIS before doing anything else on screen. However, of the 49 test cases, the clinical decision was changed only once because of the content of a KIS. The roll out of the FORCE Function is now no longer proceeding due to the focus on showing the Trak Alert when a KIS exists.
9. On Practice change / deregistration, NHS Lothian are trying to ensure that KIS and ECS content is printed since the KIS goes missing on change of Practice.
10. Some Boards are expanding the use of Vision360 to make more GP data accessible. This is system dependent and not a national solution covering all GP data.
8.5 Appendix E - Suggestions for improving use of KIS

Contributors to this report had many proposals for improvements around KIS, for example, improving how KIS operates, how KIS use could be expanded, what system changes could be made, and how information can flow back to GPs better. This section provides details of the suggestions received, which are documented here for further consideration, recognising that some suggestions conflict with others.

Improvement suggestions are grouped as follows:

A. Creating & Populating KIS content
B. Knowing a KIS exists
C. Enabling better viewing of KIS content
D. People factors in improved use of KIS
E. How System changes could improve the use of KIS
F. How data feeds could be improved
G. Improving other care professionals interaction with KIS content
H. Use of KIS in the Scottish Prison Service

A. Creating & Populating KIS content

1. Allow other groups to create and / or add KIS content. Some GPs would suggest that it isn’t clear why the GP should be required to update the KIS, since there is inadequate resource in GP practices to do this reliably. They “don’t have time to update with everyone’s ‘pet condition’”; the same point is recognised by GPs about GP’s focussing on certain conditions within their expertise.

2. KIS / ECS content should contain the relevant information: demographics; allergies; medication; repeats; smoking; exercise; etc. This should INCLUDE all priority 1 READ Codes (based on SCIMP and OSCAR), and EXCLUDE information such as STDs, Lifestyle choices, Pregnancy terminations, etc. However, some information is not being excluded as KIS readers can see some sensitive information that is unnecessary to see.

3. Increase GP awareness on KIS generation, and redacting of information. (700-800 codes are sensitive and not normally entered in Referrals or KIS. The problem is often with GPs not redacting information such as Priority 1+2 codes).

4. Better KIS preparation – reduce from too much information. Several respondents raised concern that the volume of information held in some KIS records is overwhelming due to too much content from the GP IT system, for example when a Practice copies a full Discharge Letter without assessing which key points to include. When too much text is pasted into the Special Note, the content is truncated. In each of these instances, acute clinicians are presented with a considerable assimilation challenge, ultimately causing some of these clinicians to not use KIS. Therefore the assumption that more information will be both beneficial and accessed may be incorrect.

5. Better KIS preparation – ensure enough information. A frequent criticism of KIS content is that they do not contain enough Anticipatory Care Plan (ACP) content, for example, preferred place of care, Power Of Attorney, anticipatory medication, contingency plans, carer issues, and resuscitation plans.

6. Increase awareness of what KIS information is made available to or withheld from KIS readers. Many GPs will be unaware of what the final content contains and how it is presented. One GP noted that it is “difficult to build the KIS unless everything is turned on and available”.

7. GPs who are keen to use KIS more widely would welcome clinical colleagues, from Secondary Care, Nursing Homes and / or Care Homes, proposing patients who may benefit from KIS content. This is current practice in some Palliative Care situations.
8. Ensure KIS exists for all patients with a cancer diagnosis. For some clinicians working with patients across all of Scotland, where each has a cancer diagnosis, it was noted that very few of these patients have anything at all on KIS despite the recognised benefits for patients.

9. A KIS for every patient. GPs in some practices are being encouraged to create a KIS for all patients, regardless of age or health. While this may have some benefit, and reduce the need to ask for ECS consent, there is a potential risk of clinician overload and the consequential reduction in ability to share the most useful information for those in most need of a KIS. Patients who have significant issues that need to be communicated via KIS would be “lost in the crowd”.

10. The patient’s record would benefit from having some diagnosis entered by secondary care to complement the primary care list. For example, many patients who have cancer diagnoses do not have any KIS content. This would require update access by Secondary Care.

11. Areas such as Oncology would like to write their own KIS where they can “detail OOH contact details for unit and then have diagnosis, prognosis, treatment and emergency care particularly for management of infection”. One of their justifications for “special treatment” is that disciplines such as Oncology cover several NHS Boards and sometimes the whole of Scotland.

12. A basic KIS template for practice staff to update without requiring consent would help increase the number of KIS records created.

13. Identify the “Frequent Flyers” to ensure they have a KIS.

14. The House Of Care model was mentioned as relevant to KIS being created and updated.

B. Knowing a KIS exists

15. Provide a visual prompt, or colour coding of Patient records, to highlight existence of a KIS or an ACP. Some Adastra users report that it is very much self evident - it “could not be easier” - to know when a KIS exists, but there are no visual KIS-existence clues within ECS and other clinical systems. A visual prompt would also benefit GP IT Systems as it isn’t straight forward for Practice GPs to know whether a KIS exists without having to delve into the patient’s record.

16. NHS Lothian’s visual KIS icon (KIS Alert) could be added to other NHS systems to make it easy to see and access KIS with one click in order to improve access to view KIS.

17. Provide a KIS alert (for SAS and other organisations).

18. The FORCE option could be better used to identify patients with an ACP than KIS, although it is more difficult to identify the existence of an ACP than a KIS.

19. Awareness of the national reach of ECS/KIS could be improved. One clinician reported that they hadn’t realised that KIS covered all of Scotland GPs until they found information about one of their non-local patients.

20. Develop a “culture to look” for a KIS, recognising users need robust access to KIS for this to be successful.

21. Present KIS information if available, as with the Forth Valley Clinical Portal, which is an excellent example of how KIS information can be presented easily to clinicians, without the need to search for the content or seek additional patient consent.

22. Increase awareness of the ‘Break Glass’ option available in Tayside’s Clinical Portal that enables users to view patient information while the patient is not present: It is not well known that the user has to position their mouse over a particular button to reveal a padlock. Refresher training may be beneficial as using the Break Glass requires a Reason to be entered.

C. Enabling better viewing of KIS content

23. Improve ECS password regulations: Where staff use the ECS Web access rather than Clinical Portal, password issues (expiry times / too frequent changes) reduce access and availability of important information.

19 “Frequent Flyers” is the colloquial term for certain patients who are known to attend A&E frequently

20 House of Care, developed as a progression from ‘Patient-Centred Care’, is Scottish Government’s ‘new’ model of care, which “moves to a more collaborative approach where the patient is treated as an expert in their own care, and the H&SCProf is another expert in the patient’s care” (extract from the ACP Commission Report, 2016)
24. Allow other groups to access KIS content.
25. Enable each user type to have their own view of patient information to only see what they should.
26. Enable use of Adastra in all FMS locations as some have not yet implemented.

D. People factors in improved use of KIS
27. Increase awareness that the existence of a KIS includes consent to access ECS content. Although the ECS login page states: “Patients with KIS information have consented for their data to be viewed”, requesting additional consent to access ECS content seems to be the typical way of working.
28. Make KIS an ‘opt-out’ consent model i.e. patients are IN by default therefore all information would be shared unless a patient explicitly opts out.
29. Increase general awareness and raise KIS profile:
   a. Existence of KIS
   b. Methods available to access KIS
   c. KIS consent
   d. Information transfer from / to practices
   e. Individual responsibilities
30. GPs should use the Review Date rather than the Expiry Date. Setting an Expiry Date in a Special Note causes some information not to be available on expiry, i.e. the Shared Clinical Data section containing, for example, the Special Note, Other Agencies, PMH, DNACPR, Catheter Equipment, Additional Drugs, Moving & Handling.

   Trainee GPs are used to entering an Expiry Date in Trak (which is normally set to a year later to enforce a review). This practice conflicts with how KIS is designed. Both EMIS and Vision provide a KIS REVIEW DATE.
31. Some KIS content, for example Past Medical History (PMH), does not provide the full picture when only the last ‘x’ days are shown. This issue is similar to how the ECS Medicines List was shown, where some clinicians did not look at – or did not know about - the ‘View All’ option to expand the default list. Now, the Medicines history normally includes all information from the most recent six months, although GPs can override defaults of what information is provided to ECS and / or compiled into a KIS.
32. Remove the need for perpetual consent checking: Patients assume data will be shared and do not understand why they are continually asked for consent.
33. There is a risk of misinterpretation of information by untrained staff.
34. Ensure GPs are aware that the Special Notes free text field may truncate text if they paste text in without checking.
35. Ensure GPs are aware that illegal characters (possibly @ or # symbols) in the GP IT record can cause the upload to fail or stop. This is partially fixed but it has been reported that some records are still showing incomplete.
36. Review consent model where KIS records can be created without patient consent, for example: Risk To Self / Others; Memory Issues. While this is reasonable for safety reasons, it is unclear whether this aligns with the agreed consent model.
37. Guidance on system usage should cover KIS as well as ECS in order to increase Junior Doctor awareness.
38. Provide feedback to GPs:
   a. - of KIS usage
   b. – usefulness of each KIS
   c. - KIS content rating system for each KIS (1 to 5 like a Customer Satisfaction Survey)
d. KIS content update rating system for each KIS (1 to 5 like a Customer Satisfaction Survey) on how well GPs make changes to KIS.

39. Ensure KIS information is not used for Insurance purposes.

E. How System changes could improve the use of KIS

Although GP IT changes are out of scope, suggestions for changing the GP IT systems have been retained for reference.

40. There is a preference to retain KIS content on Practice Transfer but KIS content does not transfer since Unstructured Text is not exported from GP IT Systems. KIS is inactive during the transfer process from as soon as the patient is deducted for approx 6-8 weeks (busier practices with a higher patient turnover take longer).

The Practice deregistration process is being looked at in NHS Lothian, and this issue has been documented by NHS Lothian in the paper: “LOSS OF KEY INFORMATION SUMMARY WHEN PATIENT MOVES GP PRACTICE”.

41. Upload more information to ECS, for example, ‘Created’, ‘Amended’, ‘For Review’ date fields.

42. When clinicians review the KIS content for their patients en masse (for example Palliative Care consultants), ECS Web access apparently locks users out after viewing five records.

43. Remove ePCS and subsume into KIS since there is a considerable overlap.

44. Check whether KIS records are still sent even if ‘KIS Consent Declined’ is set.

45. Solve the current Practice Transfers process, which causes data ‘branching’.

46. Resolve Clinical Portal printing issues, which have caused the regression of the access method away from Web Services back to the Web System, and reinstate ECS access from Clinical Portal.

47. Investigate feasibility of technologies such as enabling auto-login to ECS through Proximity cards.

48. Enable ECS to have more useful information for Admissions.

49. Log KIS access. The current ECS access logging does not include the capability to log users’ access to the KIS component.

50. Import ECS data into HEPMA systems (to close the loop) since coded content is lost on entry to ECS. This issue includes KIS Diagnoses such as Renal Failure.

51. There may be a potential opportunity for improvements through developer “hack days”, “mHabitat” and “mHealth”.

52. Investigate potential use of SCI Gateway for transmission of information from Practices to Pharmacies (discussions already commenced).

53. Further system interoperability would enable information to be passed more effectively between users.

F. How data feeds could be improved

54. Use a process similar to the changes to IDLs for Medicines: STOPPED, ALTERED, NEW, UNCHANGED.

As mentioned previously (section 5.3), significant changes to KIS content, such as DNACPR, could be highlighted using the ‘NEW’, ‘ALTERED’ and ‘STOPPED’ categories; other changed KIS information may be less relevant, and an ‘UNCHANGED’ category is unlikely to be beneficial.

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21 Some Boards use a Clinical Portal that has issues with printing of Prescriptions / medication ECS content. The clinical risk has persuaded at least one Board to enforce the reintroduction of ECS / KIS access via the ECS web site, removing the benefits of accessing through the Clinical Portal, while some users in other NHS Boards prefer to use the ECS Web Site rather than print via Clinical Portal.

22 mHabitat “supports digital innovation in the NHS and wider public sector from early stage discovery through to strategic planning”.

23 mHealth: The use of mobile technology in providing or using medical care.
55. DLs could contain a comment for GPs to know the changes (similar to above).
56. Update paper IDLs to electronic textual form enabling GPs to transfer information into GP IT easily.
57. Provide Discharge Letter templates that include KIS output.

G. Improving other care professionals interaction with KIS content
58. Ensure the Key points from a CYPADM are put into the Special Note (request from child care specialists).
59. There is a potential opportunity for Third Sector and Independent Care providers such as Care Homes to view KIS content.
60. Enable better two-way sharing of information between NHS and Social Care (Local Authorities have provided information to NHS since “Single Shared Assessment”).
The following points in this section were seen to depend on whether GPs continue to have responsibility for KIS content.
   If the GP continues to have responsibility:
   61. Add a system prompt for a GP to action an update to KIS.
   62. Add an e-prompt for the GP to accept the proposed content (an update or a new record) without needing to retype the content.
   63. All Health and Social Care professionals could contact the GP to indicate the need for a KIS, or that they have had an EOL conversation.
      If the GP does not continue to have responsibility for the content:
   64. A citizen record should hold KIS content (e.g. Next of Kin, preferences)
   65. The patient should control access to their content.

H. Use of KIS in the Scottish Prison Service
The 15 Scottish prisons hold approximately 8,000 prisoners across nine territorial NHS Boards. A review is currently being undertaken on the effectiveness of health care in prisons following its transfer to NHS.
66. Better sharing of information between SPS and Primary / Secondary Care.
67. Improve systems in prisons to remove dependency on hand-written processes. At present, the health information initiated within the prison environment is predominantly hand written.
68. Retain fidelity of prisoner information. A prisoner’s health history is almost always split into at least two parts since there is little two-way interaction with the GP until they are liberated. On liberation, their records may go to a GP via the normal deregistration process. Health information for some prisoners, who are either granted daytime curfew or their sentence is less than six months, will have their health information ‘branched’ into multiple strands before liberation.
69. Improve access to information for prisoners who have not been transferred to the Prison GP IT system. NHS staff working in prisons have access to ECS, and can access the Prison Vision GP IT system, therefore do not need KIS / ECS content for prisoners who have already been transferred into the Prison GP IT system. Access to health information for prisoners who have not been transferred is more challenging.
70. Improve access to information for prisoners while in Community. Home Detention Curfew prisoners are allowed out for certain parts of the day. A new pilot for prisoners allows them to do some work as a rehabilitation exercise, returning to prison every night. While their health care is provided primarily from NHS staff while in prison, a potential issue for both of these groups

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24 A prisoner is registered in the Prison GP IT system only if either their sentence is more than six months, or their clinical condition requires particular attention. Prisoners with a sentence of more than four years are likely to have been transferred from one prison to HMP Shotts, therefore their health record (predominantly paper-based while in prison) is spread across multiple locations.
occurs on change of location between prison and community as the Prison system’s health information is maintained separate from Primary and Secondary Care information, therefore changes made to either the Prison or Primary / Secondary Care systems are not replicated to the other system.

8.6 Appendix F - ECS Technical Analysis

As a separate exercise, there is an assignment being undertaken to provide technical analysis and recommendations to address functionality issues that exist within Emergency Care Summary.

Background and Context

There are currently 31 documented open issues raised against Emergency Care Summary (ECS) which have been clinically prioritised and categorised into functional areas. The analysis in the review concentrates on:

- DNACPR
- Missing / Blank KIS records
- Consent
- CYPADM

Approach

The approaches taken for the analysis were:

- Investigate associated clinical risks, identify options and undertake a SWOT analysis for each of the four prioritised categories of clinical issues.
- Undertake interviews and meetings with stakeholders, both those entering the data and those who consume the data, to ‘dig’ into issues to gain understanding from each of their experiences and perspectives.
- Based on information gathered, make recommendations on a way forward for each of these issues, recognising that for some of the issues there may not be a viable ‘technical’ fix and that a process change and / or communications may be the most appropriate solution in the short term.
- Engage with Technical Architects to analyse and document the future ECS requirements and options.
8.7 Appendix G - Patient Consent in KIS and ECS

One of NHS Scotland’s eHealth Clinical Leads points out that there is “more harm from not sharing data than sharing data”. In this vein, several CMO letters have advised NHS Boards that the use of ECS content could be increased. Some communications have tried, perhaps in vain, to reduce confusion around the restriction of data access, for example, reassuring clinicians that it is valid, where there is a need, to view a patient’s information before or after they attend.

Because the HDLs describing access are confusing, and the official ECS Access Protocol is unclear and long (20 pages), both Primary Care and services beyond Primary Care are adversely affected. Firstly, within Primary Care:

i. GPs state that there is too much risk for them to allow all health professionals to access ECS / KIS information
ii. GPs themselves typically do not understand IG risks as they are primarily trained to assess clinical risk
iii. the consent model is unclear
iv. some patient information is withheld from ECS / KIS due to the process of compiling the KIS in the Practice

Secondly, beyond Primary Care, the ‘issue’ of Consent remains a widespread challenge with significant misconceptions, and is also often a source of confusion. Some consequences of this confusion are noted:

i. access to KIS information is hindered even to users who have a valid need to view the information
ii. widening the reach of KIS information is limited
iii. a layer of unnecessary work for clinician and patient
iv. lack of clarity on whether clinicians can use KIS and ECS in non-emergency care situations (“Legitimate interest rules should be applied to allow access”)
v. many users do not appreciate that KIS consent provides consent for ECS content

Some implementations of PMS / CP only present the Consent question where KIS consent has not been set. If KIS Consent has been set, ECS information can be accessed without asking the patient. Some users are used to asking the patient for approval to view ECS content, but are not asked for consent when accessing other systems. Some suggest that “ECS has always been the odd one out”, because the data is seen to be “owned by the GP”.

Within Primary Care, there are up to 16 consent combinations for ECS, KIS and ePCS built into the GP IT systems (see the Consent Combinations table below). These determine which parts of the patient’s record are uploaded to national ECS. For example, if a patient approves the creation of a KIS, and for their KIS and ECS information to be uploaded to national ECS, the KIS will be available from the national ECS without any need for additional consent to be provided. However, if the GP fails to properly set the ‘KIS Upload Decision’ flag, ECS will not receive KIS information and therefore no KIS information will be available from ECS, and ECS information requires additional consent to be provided. Another serious problem is when a GP receives consent from a patient to create the KIS, but allows a blank KIS to be uploaded to national ECS.

The consent model is generally perceived by GPs as being too complex and cumbersome. This causes confusion among GPs, which could be the cause of some ECS records / KIS content not reaching the national ECS store and hence unavailable to Health Care professionals responsible for the care of patients who are often most in need.

There appears to be a significant lack of awareness that consent provided by a patient for a GP to create a KIS provides consent for the whole patient journey to all future viewing of KIS and ECS information by all clinicians. This issue is amplified because it is unknown in many situations that there is a KIS component within the ECS record until it is viewed, and consent is required to view ECS if KIS existence is unknown. As the proportion of records with a KIS is relatively very small, the default action is to seek consent.

As long as the current consent model is maintained, the lack of clarity of the consent model, and the lack of awareness about how consent should be applied will continue. Increasing the awareness significantly would benefit Secondary Care and other organisations such as NHS24 and SAS. Patients don’t understand why they are continually asked to give consent. This patient approval process is seen as superfluous and many clinicians stressed the point that “No patient says no to staff assessing their information.”

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25 ICO – Information Commissioner’s Office can impose fines on an individual or organisation for misuse of patient information. This applies to those creating information and to those subsequently handling this information.
26 EMIS function is ‘Consent to Send’; Vision function is ‘Decision to Send’
A simpler consent model would make KIS creation much easier for GPs, and is likely to improve the availability and quality of KIS information.

In the original ECS consent model, all patients were given the option to withdraw consent (‘Opt Out’) individually if they chose. An Opt Out of ECS means that KIS content is not uploaded. In reality, there is a relatively low number of Opt Outs across Scotland as indicated in the table.

It is advantageous to have the ability to create a KIS without requiring consent from patients, for example those who are a risk to self or others, and also to upload the KIS content to national ECS for the benefit of patient or public safety.

The absence of KIS consent could mean that health care professionals deal with potentially violent patients without being forewarned. In this scenario, the GP should exercise their ability to override consent.

Consent is required for Adastra users before seeing the ECS and KIS tabs unless provided ‘by proxy’ such as from SAS or NHS24. This consent ‘carries forward’ while the record remains open, as Adastra does not prompt for consent again until the record is closed.

**Information Sharing examples (non-ECS)**

Some H&SC Partnerships have developed “non consent information sharing agreements” between organisations (an NHS Board and Local Authority organisations) for the provision of particular services without an additional Consent Model i.e. no need to ask the patient again. These help a variety of staff to see information that could be beneficial for the care of the individual, especially when the patient is not present. In Ayrshire & Arran, Information Governance training has been given a high focus to ensure that any cross-organisation Information Governance gaps have been fully covered. Patients were also informed by letter of these new arrangements. This governance process is being used as a template for other services to replicate, and could also be used to enable AHPs\(^{27}\) to access KIS content in Ayrshire & Arran and other NHS Board / LA areas. Some organisations such as Housing are not ‘core members’ of the HSCP. Other organisations have separate Information Sharing Protocols that may require additional consent. Cases involving Child Protection or Public Safety issues are always treated with exception.

Another good example of safe and secure sharing of information across boundaries is seen across North and South Lanarkshire, where a shared information store is used by a number of agencies. This store is primarily for sharing information that is deemed very important or serious (e.g. Child / Adult Protection investigations, or Serious Crime). While all agencies can create and read information, and Public Protection Messages are shown to everyone, not everyone can see everyone else’s information.

The access to Social Care’s single system ‘SWIS’ is restricted by agency and within an agency detailing a list of all events with chronologies. The operating principles are that everyone should be able to enter information, and everyone should be able to see what they require to see for their role.

\(^{27}\) Approximately 14,000 AHPs work in Health & Social Care in Scotland across 12 discipline groupings (around 13,500 in health and around 500 in social care)
8.8 Appendix H - Consent permutations in GP IT systems

This appendix details the 16 permutations covering the ECS / KIS / ePCS consent options.

<table>
<thead>
<tr>
<th>ECS Consent</th>
<th>KIS Consent</th>
<th>KIS Send Status</th>
<th>KIS record sent?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Given</td>
<td>Given</td>
<td>Send</td>
<td>Yes</td>
</tr>
<tr>
<td>Given</td>
<td>Given</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Given</td>
<td>Declined</td>
<td>Send</td>
<td>No – Not Valid</td>
</tr>
<tr>
<td>Given</td>
<td>Declined</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Given</td>
<td>Overridden</td>
<td>Send</td>
<td>Yes</td>
</tr>
<tr>
<td>Given</td>
<td>Overridden</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Given</td>
<td>Unknown</td>
<td>Send</td>
<td>No – Not valid</td>
</tr>
<tr>
<td>Given</td>
<td>Unknown</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Declined</td>
<td>Given</td>
<td>Send</td>
<td>No – Not Valid</td>
</tr>
<tr>
<td>Declined</td>
<td>Given</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Declined</td>
<td>Overridden</td>
<td>Send</td>
<td>Yes - Only KIS note</td>
</tr>
<tr>
<td>Declined</td>
<td>Overridden</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Declined</td>
<td>Unknown</td>
<td>Send</td>
<td>No – Not valid</td>
</tr>
<tr>
<td>Declined</td>
<td>Unknown</td>
<td>Do Not send</td>
<td>No</td>
</tr>
<tr>
<td>Declined</td>
<td>Declined</td>
<td>Send</td>
<td>No – Not Valid</td>
</tr>
<tr>
<td>Declined</td>
<td>Declined</td>
<td>Do Not send</td>
<td>No</td>
</tr>
</tbody>
</table>

Table provided by Ernest Beattie, Information Governance consultant, NSS IT

8.9 Appendix I - Access Auditing

Caldicott Guardians and Information Governance Leads are involved in making sure that access to ECS is audited. The auditing of access to ECS is often administered by local IT Departments. Regular audit reports are produced by the ECS system, which are also available to all GP practices. In addition all NHS Boards have implemented the FairWarning system to detect potential privacy breaches, and to identify who has looked at a patient’s record in the event of any complaint.

SAS also have an automated audit that can be viewed from their data warehouse.
### 8.10 Appendix J - ECS & KIS patient numbers (including ECS Opt Outs)

The number of ECS and KIS patients and ECS ‘Opt-Outs’ are shown by NHS Board in this table:

<table>
<thead>
<tr>
<th>NHS Board</th>
<th>ECS Patient Records</th>
<th>KIS Patients</th>
<th>KIS Patients</th>
<th>ECS Opt-Outs</th>
<th>ECS Opt-Outs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(000’s)</td>
<td>(000’s)</td>
<td>%</td>
<td>Individuals</td>
<td>%</td>
</tr>
<tr>
<td>Ayrshire &amp; Arran</td>
<td>494.7</td>
<td>15.5</td>
<td>3.1</td>
<td>70</td>
<td>0.01</td>
</tr>
<tr>
<td>Borders</td>
<td>153.4</td>
<td>5.3</td>
<td>3.5</td>
<td>20</td>
<td>0.01</td>
</tr>
<tr>
<td>Dumfries &amp; Galloway</td>
<td>216.7</td>
<td>9.1</td>
<td>4.2</td>
<td>105</td>
<td>0.05</td>
</tr>
<tr>
<td>Fife</td>
<td>507.6</td>
<td>17.1</td>
<td>3.4</td>
<td>113</td>
<td>0.02</td>
</tr>
<tr>
<td>Forth Valley</td>
<td>420.8</td>
<td>16.0</td>
<td>3.8</td>
<td>4</td>
<td>0.00</td>
</tr>
<tr>
<td>Grampian</td>
<td>799.1</td>
<td>37.1</td>
<td>4.6</td>
<td>672</td>
<td>0.08</td>
</tr>
<tr>
<td>Greater Glasgow</td>
<td>1,694.7</td>
<td>54.3</td>
<td>3.2</td>
<td>499</td>
<td>0.03</td>
</tr>
<tr>
<td>Highland</td>
<td>404.5</td>
<td>23.3</td>
<td>5.8</td>
<td>323</td>
<td>0.08</td>
</tr>
<tr>
<td>Lanarkshire</td>
<td>773.2</td>
<td>21.8</td>
<td>2.8</td>
<td>1,261</td>
<td>0.16</td>
</tr>
<tr>
<td>Lothian</td>
<td>1,231.5</td>
<td>49.3</td>
<td>4.0</td>
<td>3,842 (542)</td>
<td>0.31 (0.04)</td>
</tr>
<tr>
<td>Orkney</td>
<td>26.2</td>
<td>1.8</td>
<td>6.7</td>
<td>56</td>
<td>0.21</td>
</tr>
<tr>
<td>Shetland</td>
<td>27.8</td>
<td>1.0</td>
<td>3.7</td>
<td>3</td>
<td>0.01</td>
</tr>
<tr>
<td>Tayside</td>
<td>535.8</td>
<td>17.2</td>
<td>3.2</td>
<td>1,064</td>
<td>0.20</td>
</tr>
<tr>
<td>Western Isles</td>
<td>37.0</td>
<td>1.4</td>
<td>3.8</td>
<td>6</td>
<td>0.02</td>
</tr>
<tr>
<td><strong>Totals</strong></td>
<td><strong>7,323.0</strong></td>
<td><strong>270.1</strong></td>
<td><strong>3.7</strong></td>
<td><strong>8,038 (4,738)</strong></td>
<td><strong>0.11 (0.06)</strong></td>
</tr>
</tbody>
</table>

- Data from Feb 2017
- ECS and KIS counts include deducted patients (who have left their practice or are deceased). Opt-Out counts are non-deducted only.
- Patient counts rounded to nearest 100; percentage values unrounded.
- ECS Opt Outs counts are shown in order to provide context for the discussion on Consent as an Opt Out excludes all ECS content including KIS.
- NHS Lothian: 3,330 Opt Outs from one practice that initially set all as Opted Out (patient list of 9,260).
### 8.11 Appendix K - Type of ECS access used by NHS Boards

This table details how each Third Party system accesses the national ECS system. It demonstrates the variety of essential systems that remain on older non-standards based technology.

<table>
<thead>
<tr>
<th>3rd Party</th>
<th>Version(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tayside</td>
<td>WCF&lt;sup&gt;28&lt;/sup&gt;</td>
</tr>
<tr>
<td>D&amp;G MedRec</td>
<td>WCF</td>
</tr>
<tr>
<td>FV Portal</td>
<td>WCF</td>
</tr>
<tr>
<td>RPV / PV</td>
<td>WCF</td>
</tr>
<tr>
<td>SAS ePRF</td>
<td>WCF</td>
</tr>
<tr>
<td>Grampian TRAK</td>
<td>WCF</td>
</tr>
<tr>
<td>Orion Portal</td>
<td>WSE&lt;sup&gt;29&lt;/sup&gt; in Live for GG&amp;C. WCF for others.</td>
</tr>
<tr>
<td>Adastra</td>
<td>WSE in Live for Police Custody Scotland &amp; Borders. WCF for others.</td>
</tr>
<tr>
<td>SAS Terrafix</td>
<td>WSE in Live (Have developed WCF)</td>
</tr>
<tr>
<td>GG&amp;C eForms</td>
<td>WSE. A replacement MedRec/eForms application is currently being developed for GG&amp;C by Orion. This new application will use WCF. No timescales on this.</td>
</tr>
<tr>
<td>Lothian Portal</td>
<td>WSE (Have started WCF development)</td>
</tr>
<tr>
<td>Lothian TRAK</td>
<td>WSE (Have started WCF development)</td>
</tr>
<tr>
<td>NHS24</td>
<td>WSE. Replacement Application by Cap Gemini will also use WSE. No timescales on this moving to production or timescales on a later phase which will include WCF interface.</td>
</tr>
</tbody>
</table>

There is concern that while NHS24 retain the older WSE standard, Boards may not prioritise the upgrading of other systems to the newer WCF standard. This would delay the ability to switch off WSE, increasing risk and ongoing costs. It is important that all systems are migrated to WCF before NHS24 are no longer WSE dependent.

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<sup>28</sup> WCF (Windows Communication Foundation) is the Microsoft framework for communication across systems. All systems that access the new ECS environment do so through WCF.

<sup>29</sup> WSE (Web Service Extensions) is an unsupported extension to the web service standard developed by Microsoft prior to the ratification of the standards.
### Appendix L - Contributing Individuals and Acknowledgements

Consultations using semi-structured interviews and various additional communications were the main contributing sources for this report. Individuals and groups from various organisations and disciplines contributed.

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
<th>Role(s) / Team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Blythe Robertson, Helen Stevens</td>
<td>Scottish Government</td>
<td>Self Management And Health Literacy; House of Care lead</td>
</tr>
<tr>
<td>Tim Warren</td>
<td>Scottish Government</td>
<td>Palliative and End of Life Care, Person-Centred and Quality Team</td>
</tr>
<tr>
<td>Mark Darroch</td>
<td>NHS GG&amp;C</td>
<td>NMAHP / Mental Health</td>
</tr>
<tr>
<td>Mark Fleming</td>
<td>NHS Ayrshire &amp; Arran</td>
<td>IM&amp;T</td>
</tr>
<tr>
<td>Phil Keegan</td>
<td>NHS Lanarkshire</td>
<td>eH Clinical &amp; Sexual Health</td>
</tr>
<tr>
<td>Andy Winter</td>
<td>NHS GG&amp;C</td>
<td>GP OOH</td>
</tr>
<tr>
<td>Joan Barr</td>
<td>NHS GG&amp;C</td>
<td>Speciality Doctor in Palliative Medicine</td>
</tr>
<tr>
<td>Charlie Hall</td>
<td>Victoria Hospice, Kirkcaldy</td>
<td></td>
</tr>
<tr>
<td>Juliet Spiller</td>
<td>Marie Curie &amp; NHS Lothian</td>
<td>Consultant in Palliative Medicine and National Clinical lead for DNACPR policy review</td>
</tr>
<tr>
<td>Miriam Sinclair</td>
<td>NHS Lanarkshire</td>
<td>Acute Medical</td>
</tr>
<tr>
<td>Bruce Watson</td>
<td>NHS Lothian</td>
<td>Acute Pharmacy</td>
</tr>
<tr>
<td>Paul Miller</td>
<td>NHS GG&amp;C</td>
<td>Primary Care GP (and member of SCIMP)</td>
</tr>
<tr>
<td>Pete Gregson; John Steyn</td>
<td>NHS Lothian</td>
<td>eHealth</td>
</tr>
<tr>
<td>Steve Baguley</td>
<td>NHS Grampian</td>
<td>eHealth Clinical Lead</td>
</tr>
<tr>
<td>Carey Lunan, Jim Marple, Amanda Fox</td>
<td>NHS Lothian</td>
<td>ACP / PACT Team</td>
</tr>
<tr>
<td>Ian Blair</td>
<td>NHS Orkney</td>
<td>Primary Care GP</td>
</tr>
<tr>
<td>Philip Korsah, Anne Hendry, Kathleen Macuire, Morag McNulty</td>
<td>NHS Ayrshire &amp; Arran</td>
<td>Acute – various</td>
</tr>
<tr>
<td>Andrew Cowie, Janet Binnie, Chi Kong Cham</td>
<td>SGPC / NHS Tayside</td>
<td>GP, Clinical Portal</td>
</tr>
<tr>
<td>Beena Raschkes</td>
<td>NHS Tayside</td>
<td>eHealth Clinical Lead &amp; Primary Care GP</td>
</tr>
<tr>
<td>Jim Docherty</td>
<td>NHS Highland</td>
<td>eHealth Clinical Lead</td>
</tr>
<tr>
<td>Lynne Prophet &amp; Annabel Howall</td>
<td>NHS Borders</td>
<td>eHealth &amp; Palliative Care</td>
</tr>
<tr>
<td>Neil Kelly</td>
<td>NHS Dumfries &amp; Galloway</td>
<td>eHealth Clinical Lead &amp; Primary Care GP</td>
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<tr>
<td>Esther Davidson</td>
<td>NHS Fife</td>
<td>A&amp;E Nurse Supervisor</td>
</tr>
<tr>
<td>Brian Lawson</td>
<td>NHS Golden Jubilee Hospital</td>
<td>eHealth</td>
</tr>
<tr>
<td>Tom Byrne</td>
<td>NHS HIS</td>
<td>Prisons</td>
</tr>
<tr>
<td>Keith Burns</td>
<td>NHS Western Isles</td>
<td>Secondary Care GP &amp; Primary Care GP</td>
</tr>
<tr>
<td>Susan Kelso</td>
<td>Scottish Government &amp; NHS Lanarkshire</td>
<td>AHP Lead</td>
</tr>
<tr>
<td>Lesley Mackenzie</td>
<td>Grampian Local Authority</td>
<td>Care coordinator – Banff</td>
</tr>
<tr>
<td>Robin Lawrence; Gerry Buchanan</td>
<td>NHS SAS</td>
<td>National Clinical Performance Manager (Ref’d); IT Clinical</td>
</tr>
<tr>
<td>Ailsa McAllister</td>
<td>HSCI – Dundee</td>
<td>Homelessness, Older People, Outcomes and Self-directed Support</td>
</tr>
<tr>
<td>John Sandbach</td>
<td>NHS24</td>
<td>Head of Clinical Systems Development</td>
</tr>
<tr>
<td>Sally Patrick</td>
<td>NHS Forensic Medical Services</td>
<td>Head of Service, Dundee Police Custody Suite</td>
</tr>
<tr>
<td>Fiona Stratton; Martin Williamson;</td>
<td>Edinburgh CHP and Edinburgh Council</td>
<td>Intermediate Care Service Manager</td>
</tr>
<tr>
<td>Name</td>
<td>Organisation</td>
<td>Role(s) / Team</td>
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<td>-------------------------------------</td>
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</tr>
<tr>
<td>Margaret French</td>
<td>NHS Lanarkshire</td>
<td>Health &amp; Social Care Manager</td>
</tr>
<tr>
<td>Karen Gray</td>
<td>North Lanarkshire Council</td>
<td>ACP Steering Group</td>
</tr>
<tr>
<td>Orla Prowse</td>
<td>Edinburgh Community Physiotherapy Service, HSCP</td>
<td>Home and Associated Services Service Lead</td>
</tr>
<tr>
<td>CarolAnn Topping</td>
<td>NHS State Hospital</td>
<td>NHS Practice Nurse</td>
</tr>
<tr>
<td>Paul O'Neill</td>
<td>HMP Shotts</td>
<td>NHS Service Manager</td>
</tr>
<tr>
<td>Karen Jensen</td>
<td>NHS GG&amp;C and Inverclyde Council</td>
<td>Senior Occupational Therapist</td>
</tr>
<tr>
<td>Janice Donnachie</td>
<td>Inverclyde Council</td>
<td>Occupational Therapist</td>
</tr>
<tr>
<td>Andy McCleary</td>
<td>NSS IT</td>
<td>ECS Service Manager, NSS IT</td>
</tr>
<tr>
<td>Ernest Beattie</td>
<td>NSS IT</td>
<td>Information Governance lead, NSS IT</td>
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<tr>
<td>Scott Hall</td>
<td>NSS IT</td>
<td>ECS Review</td>
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