

# ALISS

REPORT 1

Access to Local Information  
to Support Self Management  
2009-2013



*This report is dedicated  
to the memory of Derek Hoy*

*The ALISS story is recorded in two connected reports:*

**REPORT 1  
ALISS 2009 – 2013**

This Report describes development of the original Access to Local Information to Support Self Management system. ALISS was designed to support self management through linking ideas about health literacy, social innovation, innovative technology and individual and community connectedness.

**REPORT 2  
ALISS 2013 – JANUARY 2016**

Report 2 describes how ALISS was further developed between April 2013 and January 2016, to become A Local Information System for Scotland.

# Welcome from the CEO of the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE)<sup>1A</sup> and Scottish Government share a view that key features of our future caring systems will be that they place a high value on the inter-connectedness of formal and informal support. We share a common ambition that Scotland is a place which offers a positive and healthy future for all of us – young and old, people living with disabilities, those living with multiple long term conditions and paid and unpaid providers of care. This means improving links at all levels, between individuals, teams, services and systems.

Developing the collaborative infrastructures needed to improve connectedness is hard, however this report describes how the ALISS project set about doing just that, to develop a modern, practical tool, fit for the 21st century. The system which emerged, is a shining example of Scottish innovation, where imagination has been matched with cutting edge technology.

From the start, the ALISS team looked at how modern technology and social networks could be harnessed for the common good, and to do this in a way which would provide a signposting tool, and useful intelligence about support for prevention and self-management, required by planners and Integrated Joint Boards and policy makers in Scottish Government.

It was the open and collaborative approach which is worth noting - the method was not to develop a IT health project in the traditional way, but to create an open system which took account of inequalities in health and which was informed by the lives of people living with multiple conditions and those with low levels of literacy. The project team engaged school pupils, librarians, police, service designers and others in the community in their quest to make a useful and sustainable tool, developing a platform for innovation, which can be now used in many different ways.

Reciprocity is at the heart of ALISS. In Scotland as in other countries, there is a growing consensus that there is untapped potential in developing a more reciprocal approach, one which means **“we’re all in this together”**, where effort and benefits are equally shared between people living and working in communities. Such an approach is vital in addressing the growing problem of loneliness, inequalities in health, generating an ethos of co-ownership of our health and social care services, and indeed, of all of our local and public services. ALISS represents this and much more and so I very much welcome this report.

**Ian Welsh, OBE**

**Chief Executive of the Health and Social Care Alliance Scotland**

<sup>1A</sup> <http://www.alliance-scotland.org.uk/>

# Joint Foreword

## Sir Harry Burns, Chief Medical Officer for Scotland, 2005 – 2014

Many years ago, I was a surgeon at the Royal Infirmary in Glasgow. We served patients in the east end of the city, an area which was then, and still is, one of the poorest in the UK. We spoke to patients about their smoking, eating and alcohol habits and how they were damaging their health. I was struck by the degree of negativity and hopelessness I often encountered. Patients frequently told me that life was miserable and they weren't interested in living any longer than they had to.

Over the years, it became clear that a lack of social connectedness and the resultant loneliness was a major contributor to the unhappiness and despair felt by so many of our patients. It was obvious that the conventional approach which viewed people living in such circumstances as having problems, which had to be fixed by outsiders, was not going to work. People were defined in terms of their deficiencies and problems. Evidence suggested the need for a different approach which concentrated on helping individuals and communities to solve their own problems through discovering and making use of the assets and abilities they had which were often unrecognised.

ALISS emerged at a time when we were considering how concepts such as asset-based approaches could be harnessed to help Scotland become a place where we could all enjoy health and wellbeing. The evidence of the biological links between environmental factors and wellbeing supported the importance of strengthening connectedness at all levels –

between individuals, families, teams, services and systems. It seemed that a key feature of our future caring systems should be that they place a high value on social contact and the inter-connectedness of formal and informal support. Yet, for many complicated reasons, formal and informal assets which could support people to be in control of their lives could be right on their doorstep yet not be accessed by people who could benefit most.

In developing a self management programme, the Scottish Government set about putting theory into practice. The ALISS project asked people **“what keeps you well?”** and found that people were often simply looking for a kindred spirit and that most didn't know what assets were in their community or didn't have the confidence to join in. Most important was that people had no way to share their own valuable knowledge of local support. Addressing this disconnectedness was at the heart of developing ALISS.

The History of ALISS tells an interesting story, not just about producing innovative technology, but also about the nature of adopting new ideas. This report represents a reflection on the challenges of shifting from a traditional approach, where institutions control and quality assure information, to a more open approach where information is “let go”, where people, groups and organisations share their knowledge and support each other. The resulting system emerged through listening to people's experiences, validating concepts and taking a few risks. Links were made between people's stories and cutting edge technology using open source software. The ALISS system in use today emerged

through making these big connections. It is a practical tool to distribute information and a platform for innovation. It has the potential to be used in public service in many ways.

I welcome the History of ALISS, which itself is a good story. It makes an excellent contribution to our deeper understanding of the benefits of engaging citizens as co-producers of public value and harnessing 21st century technology for the common good.

**Sir Harry Burns Professor of Global Public Health, University of Strathclyde Chief Medical Officer for Scotland, 2005 – 2014**

### **Professor Craig White, Executive Sponsor and Chair of the Scottish Government Project Board that Commissioned the ALISS Demonstrator Project, 2009 - 11**

The ALISS project is one of the most innovative digital projects, if not the most innovative, digital project that I have had the pleasure to be involved with. From the outset, Christine Hoy, Derek Hoy, Peter Ashe and Andy Hyde had a vision of what would be possible. The original bid for support was strongly linked to policy development on person and community strengths, coupled with the benefits of ceding power and promoting mutuality through sharing what people said helped them to live well with long term conditions.

There were colleagues who wanted to ensure that professional editing and moderation of submissions to ALISS were designed into the

work, others who struggled to understand how the commitment to put people at the centre of health and social care could be the guiding principle of “a website”, as they understood it.

I remember the energy and enthusiasm in the team after the idea was pitched to Sir Harry, then the Chief Medical Officer for Scotland. Sir Harry’s response was “**I see – you’re letting information go**”, he understood that transformation was more likely to happen through enabling people to share, connect and describe what worked best for them, their condition, their community and their personal reality.

It has been a pleasure to watch ALISS grow from its early days and in particular to see it flourish in the fertile soils created by all who work at the Health and Social Care Alliance Scotland.

ALISS would not be what it is, were it not for the skill and involvement of the late Derek Hoy. Derek’s presentations to the Project Board were way ahead of their time in terms of quality, presentation and power – his quiet, yet clear and authoritative approach to the brief had a huge impact on everyone who heard his proposals for the development of ALISS.

Congratulations to everyone who has made ALISS such a success and thank you to everyone across the country who has contributed to this work – a shining example of the power of connecting, sharing and co-production.

**Professor Craig A White  
FRCP Edin FBPsS  
Healthcare Quality and Strategy Directorate,  
The Scottish Government**

# Summary

This document is a summary of the 2009 - 2013 phase of development of the Access to Local Information to Support Self Management (ALISS) project. The project was set up in January 2009 and managed by the Self Management Programme of the Scottish Government in close partnership with the Long Term Conditions Alliance Scotland, which later became known as the Health and Social Care Alliance Scotland (the ALLIANCE).

In 2011, management was transferred to the ALLIANCE and became known as A Local Information System for Scotland (and so retaining the acronym ALISS), however there was little development during 2012 due to illness. Activity resumed in 2013 when Jane Ankori was appointed Director of the ALISS Programme.

## The Policy Context

The policy context for the project came from the Better Health Better Care Action Plan which referred to the Scottish Government's commitment to encourage self management of long term conditions and maintain a "grass roots" approach:

**"Health and social care professionals need quick access to information. Despite good local examples, there is no standard referral system between NHS and non-NHS organisations. A self management framework is therefore required in each area to identify existing support systems and provide a map for staff and the public."**<sup>1</sup>

The Self Management Strategy for Long Term Conditions in Scotland (2008), "**Gaun Yersel**" referred to the need for access to information for successful self management:

**"Self management is an individual's responsibility but they must be given**

**the information, skills, confidence and support to self manage successfully..."**<sup>2</sup>

The early period of ALISS development coincided with an increasing interest in an assets approach, in Scotland and elsewhere. This was championed by Sir Harry Burns, Scotland's Chief Medical Officer, in his Annual Report (2011).<sup>3</sup>

ALISS aimed to produce a practical tool to support an assets approach and protective factors needed by individuals and communities to maintain and enhance a culture of health. Development was framed with reference to activity in Scotland around inequalities in health, health literacy, self care and self management of long term conditions. ALISS intended to do this by presenting a way for people to connect and be assets to each other and their community.

## The ALISS Vision

Rather than creating another website or single solution, the plan was to develop an infrastructure which allowed existing information about services to be linked and better utilised, and to ensure that this infrastructure was designed by people who would use it. The technical solution to linking data in this way did not exist and so the ALISS project was ambitious and innovative.

The ALISS team aspired to avoid a traditional top down approach, which would typically deliver an information technology tool ready-made to users. It was intended that by connecting the insights of people living with long term conditions, creative service designers and experts in computer technologies, a rich resource could be developed. The project intended to deliver a service rather than bits of data; to connect people, to allow them to contribute information rather than simply consume it, and so as much effort was

1. Scottish Government. 2007. Better Health Better Care Action Plan. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.scotland.gov.uk/Publications/2007/12/11103453/0>

2. Scottish Government and the Health and Social Care Alliance Scotland. 2008. The Self Management Strategy for Scotland. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.scotland.gov.uk/Publications/2008/10/GaunYersel>

3. Scottish Government. 2011. Chief Medical Officer Annual Report 2010 Assets for Health. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.gov.scot/Publications/2011/12/14120931/6>

spent on strengthening human relationships and engaging individuals, groups and organisations, as was spent on technical development.

## Aim

The aim of the project was simply to develop an electronic framework which would make the resources which support people to self manage easy to find. The open approach needed clarity about what it was not doing, for instance the remit was:

- Not to produce a static database, directory, or website
- Not to take a traditional approach to quality standards to content as it would not be practicable to “kitemark” user generated content (though quality assured information would be included, and safeguards would be put in place)
- Not to present clinical information (for example information about diabetes).

## What ALISS aspired to address:

- People living with long term conditions may only have contact with health professionals for about three hours a year. The rest of the time they may be disconnected from support, which is a particular concern for people living with multiple conditions
- Strengthening relationships enables the best use of local assets, knowledge and infrastructure, which has particular relevance in Scotland’s deprived areas
- People, groups and public services providing support do not have an obvious way to connect and mutually support each other
- Assets, such as local resources, are hard to find as they are often informal and not easily discovered by word of mouth or an internet search
- Online searches to find local resources are a challenge and traditional approaches of creating online directories do not reflect how people seek and use information<sup>4</sup>

- Valuable information is often scattered on paper and over the web; lists of resources are held in different places like local libraries, health centres, GP practices, schools, social care and voluntary sector organisations. Information about support may be there but is unconnected and hard to find.

## Project Approach

The solution for linking data to support self management did not exist in Scotland or any other country at the time. The team explored systems world-wide to ensure a suitable technical solution did not already exist, including systems used in third sector, public and private sectors. No suitable technical solution was found and so the Project Board agreed to develop a prototype.

An open approach was taken to all aspects of the project to ensure the technology was properly informed by users, and that material produced along the way could be shared and reused. For example, all material from the open innovation process is freely available and the technical architecture was developed in open source.<sup>5</sup> The algorithm for the ALISS platform was generic, so can be applied to other areas of public services. Publishing the Engine code as open source meant others could re-use the index-style platform for many other purposes (beyond health).

## Making a Case for ALISS

Co-producing a system in open source, which involved crowd-sourcing information, was unfamiliar and so a robust case had to be made to the Scottish Government and others. This was achieved through three inter-connected workstreams: Health Literacy, Communities and Technical Architecture. These workstreams produced evidence that people and staff valued personal and community support, but found it difficult to find information on local resources.

Meantime, projects were emerging in Scotland, which supported the case for ALISS as a useful tool for professionals. The aim of the Links Project<sup>6</sup>

4. Hyde, A. 2008. About: November 2008. Being Patient. [Online]. [Date accessed: 03/06/15]. Available from: URL <http://intheblongterm.wordpress.com/about/>

5. Github. 2010. The ALISS Engine Code. [Online]. [Date accessed 03/06/15]. Available from: URL <http://github.com/snowcloud/Engineclub/>

6. Scottish Government. 2012. Links Report: Developing the connections between General Practices and their communities. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.scotland.gov.uk/LinksReport>

(2010), was that ten general practices would explore their connections with the community they served. Six of the ten practices were in the most deprived areas of Glasgow (recruited from the General Practitioners at the Deep End<sup>7</sup>). Conclusions were that primary care staff were unaware of most of the rich resources in their area and were interested in developing and maintaining connections with local providers of support, but would need technology to do so. The Links Project recommended that the ALISS system should be implemented in primary care to improve access to online local information.

Other activities included asset mapping workshops, where local people got together to identify places and services that were valuable to them. Discoveries were quickly translated into an index record in ALISS, making assets available to others for the first time and creating a way to build new services.

## Innovation

One of the team's ambitions was to explore the idea that ALISS could become a platform for innovation. With an ALISS Engine (the software framework) in place, an environment could be created where people with long term conditions and others could develop their ideas into working services or social enterprises. The ALISS project realised that to create a technical infrastructure that could respond to diverse information needs, it was vital to involve potential users in the design process. The team was inspired by hackdays, BarCamp and Social Innovation Camp methodologies, which were described by the Young Foundation in the Open Book of Social Innovation.<sup>8</sup> In 2010, the ALISS team adapted these methodologies, to create a series of workshops to bring together people living with long term conditions, practitioners, researchers, service designers, managers, web developers and information providers.

Creating this environment fostered new ways of thinking. The team gained valuable insights into what was really important to people, such as loneliness, social isolation, the confidence needed to negotiate the health and social care service, connect with other people and help each other. Software developers heard

people describe their experience of negotiating disconnected systems and seeking community resources. There was a general consensus that people were content to make their own minds up about the quality of information and did not see the need for professionals to be "gatekeepers".

One of the important learning points was the emphasis people placed on finding people as well as activities and clubs. Many wanted to find a kindred spirit who could act as a guide to opportunities and sources of help. The ALISS technical architecture was therefore developed to be flexible and to keep in mind "people helping people" aspect of self management.

## What ALISS produced

Three requirements were identified to develop a whole-system to support self management:

- The ALISS Engine (the central processing component): to provide the technical infrastructure to collect, index and re-present information.
- The ALISS Service: ALISS as a collaborative, providing a range of services to support people and organisations.
- The ALISS Community: bringing together like-minded people, making connections between initiatives and encouraging people to join in.

## Products 2009 – 2010:

Phase 1 of the technical development involved constructing a working model of ALISS based on user experience. The components were:

- Desk research: an online search of health board websites for local support
- A personal video diary to develop methodology for capturing the experience of people seeking local information ('Being patient')<sup>9</sup>
- The ALISS Health Literacy report<sup>10</sup>
- A Tutor Pack for Adult Literacy Tutors.

7. GPs at the Deep End, information available from: URL <http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/deepend/>

8. The Open Book of Social Innovation, [online] The Young Foundation, March 2010, <http://youngfoundation.org/publications/the-open-book-of-social-innovation/>

9. Hyde, A. 2008. About: November 2008. Being Patient. [Online]. [Date accessed: 03/06/15]. Available from: URL <http://inthelongterm.wordpress.com/about/>



## Products 2010 – 2011:

- Phase 2 of the technical development: implementing the ALISS Engine (see explanatory screencast)<sup>11</sup>
- www.aliss.org - a website to share the ALISS story with links, resources and project information
- A collaboration with Snook, service designers who helped facilitate an Open Innovation Process
- A report on the Open Innovation Process
- An ALISS lesson plan for secondary school, a collaborative initiative with Edinburgh Trinity Academy which won a major European schools competition
- A proposal for brokerage service to link social care and health projects with service design students in art colleges (this was called Matchable<sup>12</sup>)
- Asset mapping workshops, and Asset Mapping in a Box, a toolkit to syndicate the asset mapping process across Scotland
- Guidance on how to collaboratively curate information on local resources
- Numerous screencasts, videos, presentations and reports.

## Project budget

The ALISS project developed a national IT system on a comparatively small budget, however it must be acknowledged that a great deal was accomplished through contributors' enthusiasm and goodwill. The budget for 2009 – 2011, including technical development was £149,400.

Staff costs were low as the Self Management Programme absorbed the ALISS project within existing work. Technical development was commissioned through the usual Scottish Government procurement process.

## 2009 – 2010

<b>Technical development</b>	<b>£43,600</b>
<b>Health Literacy workstream</b>	<b>£17,000</b>
<b>Communities and OIP</b>	<b>£25,200</b>
<b>Total = £85,800</b>	

## 2010 – 2011

<b>Technical development</b>	<b>£49,100</b>
<b>Communities and OIP</b>	<b>£14,500</b>
<b>Total = £63,600</b>	

## ALISS beyond 2012

The ALISS project began with an idea to use the web to link data sources around Scotland for the benefit of those living with long term conditions. By 2011, it had the potential to become a local information system for Scotland and a hub for a range of activities which would make it easier to make vital social and information connections to support staff and maintain and improve health and wellbeing in communities.

Following an options appraisal in May 2011, the management of the project was transferred from the Scottish Government Self Management Programme to the ALLIANCE. The community, which had grown around ALISS, was optimistic that the ALISS Engine had the potential to pioneer a platform for developing information services, providing opportunities for new mash-ups and applications not yet imagined. By 2012, ALISS was becoming an entity, which attracted interest across a range of disciplines and provided a unique focus for innovation. In April 2013, ALISS entered a new phase of development when Jane Ankori was appointed Director of the ALISS Programme, and ALISS became A Local Information System for Scotland.

10. Scottish Government. 2009. ALISS Health Literacy Report, [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL [http://www.alliance-scotland.org.uk/download/library/lib\\_5461d6ec4ca33/](http://www.alliance-scotland.org.uk/download/library/lib_5461d6ec4ca33/)

11. Andy Hyde. 2011. How can the ALISS engine help me? [Online]. [Date Accessed 03/06/15]. Available from: URL <http://vimeo.com/22614113>

12. Blueprint for Matchable (online), Snook, 2012, available from [https://matchablehealth.files.wordpress.com/2012/07/matchable\\_finalblueprint\\_sd\\_ver3.pdf](https://matchablehealth.files.wordpress.com/2012/07/matchable_finalblueprint_sd_ver3.pdf)

# Introduction

This report describes the first phase of the Access to Local Information to Support Self Management (ALISS) project, now known as A Local Information System for Scotland. The report refers to the period of development from January 2009 to January 2012. During the period January 2012 to April 2013 the ALISS system was working and being used, but development stalled in spring 2012, due to illness.

The early phase of ALISS was developed with an enthusiasm to develop technology to share content in a national online tool. But there were challenges along the way as the idea of crowd sourcing information and pooling traditional directories of resources was both

novel and unfamiliar. However, there was confidence that a rich resource could be co-produced by linking Scotland's talent for user led innovation, the insights of people living with long term conditions, service designers and experts in computer technologies.

The team kept an eye on emerging ideas about the future of healthcare and the fast moving world of social media and digital technology. Development was influenced by Scotland's persisting health inequalities, health literacy, self management, how to get innovative ideas adopted, open source technology and the huge surge in use of mobile technologies. The ALISS system which emerged, is a reflection of all of these ideas.

## The Policy Context

The policy initiative for ALISS was the Scottish Government's strategy for a healthier Scotland - Better Health Better Care Action Plan (2007)<sup>13</sup>. This set out the Government's programme to deliver a healthier Scotland by helping people to sustain and improve their health, especially in disadvantaged communities, and ensure better, local and faster access to health care. Better Health Better Care stated that a **"self management framework is required in each area to identify existing support systems and provide a map for staff and the public. For instance details on group activities, condition specific and generic self management programmes, mental health services, motivational coaching; carer and family support and telecare support."**

The mutual theme described in Better Health Better Care was developed in the Healthcare Quality Strategy for NHSScotland, which referred to **"valuing diversity, promoting a person-centred approach and involving people in the design and delivery of healthcare."**<sup>14</sup>

The Self Management Strategy for Long Term Conditions in Scotland (2008), **"Gaunder Yersel"** (probably the first government strategy developed by people) referred to the need for access to information for successful self management:

**“Self management is an individual's responsibility but they must be given the information, skills, confidence and support to self manage successfully...”**<sup>15</sup>

ALISS was developed in line with recommendations made in several reports including the GPs at the Deep End initiative<sup>16</sup>, the Christie Commission<sup>17</sup>, the Auditor General's Report on Inequalities in Scotland and Scottish Government's eHealth Strategy (2011).<sup>18</sup>

13. Scottish Government. 2007. Better Health Better Care Action Plan. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.scotland.gov.uk/Publications/2007/12/11103453/0>

14. Scottish Government. 2010. The Healthcare Quality Strategy for NHSScotland. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.gov.scot/resource/doc/311667/0098354.pdf>

15. Scottish Government and the Health and Social Care Alliance Scotland. 2008. The Self Management Strategy for Scotland. [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.scotland.gov.uk/Publications/2008/10/GaunYersel>

## Why ALISS?

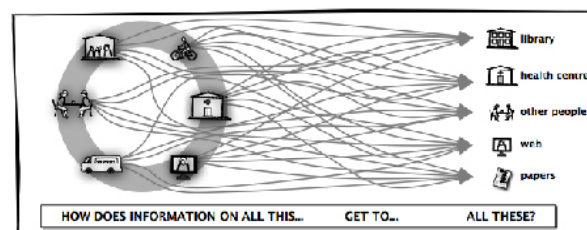
A fundamental requirement for living well is the opportunity to connect to others and to be able to find, understand, share and use information. Without this opportunity, people are less able to make connections, support each other, access resources and share decisions about how to live well. A sense of connectedness, which is vital for people who are vulnerable through a mix of circumstances such as early life trauma, inadequate incomes, poor education and poor mental and physical health and wellbeing, was articulated by Sir Harry Burns in numerous presentations and reports.

The conundrum ALISS set out to address was that despite living in an increasingly technological, networked environment, it was still hard to find support, although it may be on the doorstep. This was due to a mismatch; providers of support were unable to reach their intended users because there are too many places to put their information and there were too many places for people to find information – what was missing was the vital connection between the two. This gave ALISS the strapline: **“1 place to put” “1 place to find”** information.

## What ALISS intended to address:

- Many people living with long term conditions may have contact with health professionals for about three hours a year, the rest of the time they are likely to be disconnected from formal support
- People and groups (informal and institutional) providing support do not have an obvious way to connect and mutually support each other
- Making these connections will make best use of local assets, knowledge and infrastructure
- Assets are hard to find, as they are often informal and not easily discovered by word of mouth or an internet search
- Online searches to find useful local resources are a challenge and traditional approaches of creating online directories do not reflect how people and staff seek and use information<sup>19</sup>
- Valuable information is often scattered on paper and over the web; lists of resources are held in different places like local libraries, health centres, GP practices, social care and voluntary sector organisations. Information about support may be there but is unconnected, hard to collect and hard to find.

15 min per month  
= 3 hours per year



People offering support have to publicise it in many ways.

People who provide this information have many places to find it.



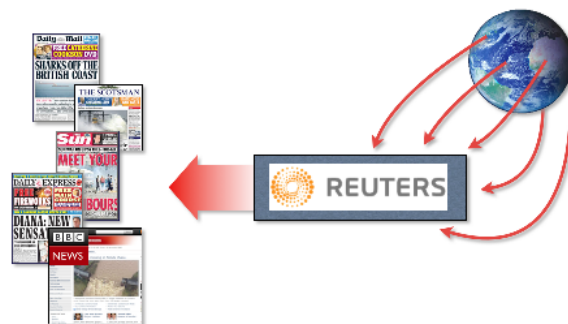
16. GPs at the Deep End, information available from: URL <http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/deepend/>  
 17. Scottish Government, 2011. Commission on the Future Delivery of Public Services [Online] [Date accessed 02/02/15] <http://www.gov.scot/Publications/2011/06/27154527/0>  
 18. The Scottish Government, 2011. eHealth Strategy, [online] accessed 10/08/15, available from <http://www.gov.scot/Resource/Doc/357616/0120849.pdf>  
 19. Hyde, A. 2008. About: November 2008. Being Patient. [Online]. [Date accessed: 03/06/15]. Available from: URL <http://inthelongterm.wordpress.com/about/>

## Developing an ecosystem to support connections

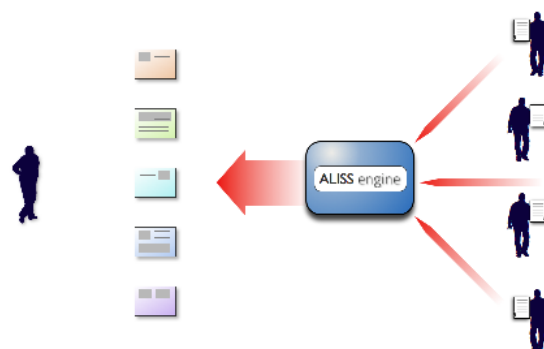
The team set out to find out what support people said they needed to live well and to make that support findable. Examples of failed expensive Information Technology (IT) projects supported the view that ALISS should not be traditionally delivered “ready-made” to users. The team wanted to develop both social and technical processes to ensure products were co-designed and adopted with those likely to benefit - people living with long term conditions, their families and carers, people with poor levels of literacy and people and staff living and working in areas of deprivation.

It was important not to add to the abundance of information by creating another website, but to create an infrastructure which allowed existing information about services to be linked and better utilised. The team wanted to explore the idea that people themselves are “information hubs”, and find a way to “let go” and de-institutionalise information, clear a path and distribute control to individuals and communities who “know the streets”.

Without a working model, explaining the concept and purpose of ALISS was difficult, the team found it was useful to ask people to think of the system as having the same function as the news agency Reuters; agencies across the world don't laboriously gather all information themselves, news is syndicated and organized for efficiency.



*ALISS is like Reuters, collect news & pass on*



*Figure 2 ALISS has same function as Reuters*

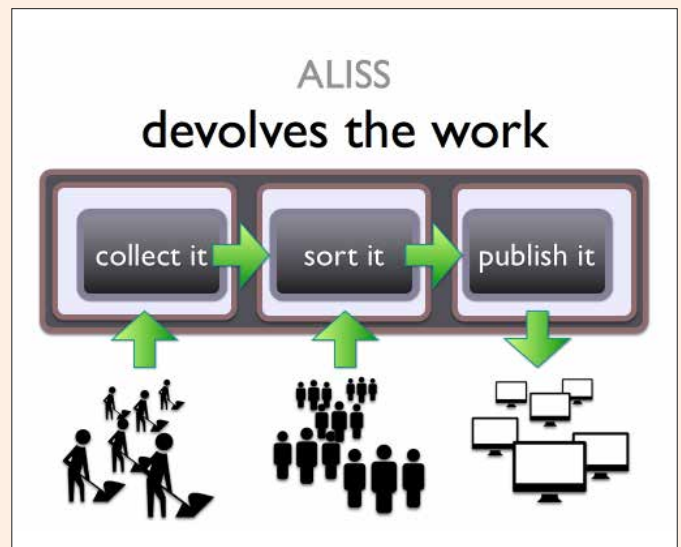
# Making a Case for ALISS

## “Why not use Google?”

Developing a system in a traditionally constructed environment was challenging. The ALISS “community” had to describe the value of informal, local sources of support for people living with long term conditions and their carers, and attract support for “letting go” information. Questions were rightly asked about the validity of what was proposed, including **“why not just use Google?”** The ALISS response was:

- ALISS would publish (index) resources, which are not already online
- The ALISS curation process would improve metadata
- Resources published on ALISS feeds would be linked to more resources
- There is little control over Google indexing (users can pay to promote resources)
- Google requires good information and health literacy
- Google was being affected by spam.

The lead software developer predicted that if the ALISS Engine worked according to plan, then ALISS would improve searches on Google. This was because the curation process would improve metadata (and once the Engine was working this was proved true).



Making a case for ALISS was approached in four ways:

1. Desk research – an online search for local resources on Scottish health board websites.
2. A personal video diary, recording a walk round a community, looking for support (Being Patient).
3. A description of the experience of people attending adult literacy class as they looked for support to live well in their community (the ALISS Health Literacy workstream).
4. The ALISS Communities workstream, an innovative approach to co-producing local directories of information (Curriculum for Excellence workstream).

## 1. Online search for local resources on health board websites

There were two stages to this process, first a desk exercise which involved an online search for local support in the fourteen health boards in Scotland. Three issues were chosen - arthritis, depression and finding local help to lose weight. The process was recorded in terms of what information was found, number of clicks needed, how long it took and how easy it was to find support. The second stage was to make phone contact with site administrators with a fixed set of questions.

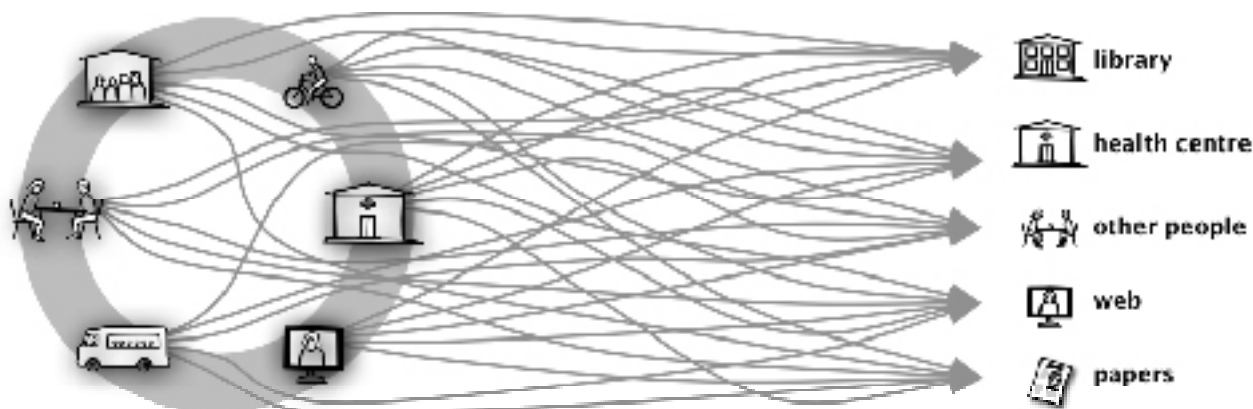
The findings indicated that there was little information about community resources on health board websites and providers of information found collecting, updating and quality assuring local information very time consuming.

## 2. Being Patient

**"Being Patient"**, the second ALISS activity in early 2009, could be described as "light touch" ethnography. A member of the team, with experience of digital technologies, set up a blog and recorded a video of his venture round his neighbourhood looking for support for the same three issues - arthritis, depression and help to lose weight.

Recording the video provided insight into the practicalities of capturing the lived experience of people seeking support in the community. This exercise was useful in the next step - the Health Literacy workstream, as the team learnt how to track journeys, for instance, was it best to ask participants to use a Dictaphone, camera, video, keep a diary on paper, use a blog? Being Patient led to the decision to abandon an idea to use disposable cameras, as participants would have been put in the awkward position of asking permission and gaining consent. An example of an experience captured in Being Patient:

**"Quick dash to the supermarket first thing this morning. There was an announcement about hiring wheelchairs from Lothian Shopmobility to help with shopping – "just ask at customer services for more details." So back home I'm searching for a link and Google takes me to Edinburgh Council's website. Unfortunately the link to "Shopmobility-Scotland" is broken. This may be a small point about the web presence, all I have to do is go to customer services and ask, but if I hadn't heard that announcement I wouldn't have known the service was available at my local supermarket. Information about self management classes and support groups is important, but services such as help with shopping could make a difference to someone with mobility problems. Maybe we need to find ways of building that bigger picture of all the different services that can help you by bolting on 'stuff you might not have thought about' next to the more obvious condition-related info?"**



# The ALISS Health Literacy worksteam

The next step was to capture the experience of adult learners attending a literacy class, as they looked for local sources of support. The idea was to gather their feedback about **“does it all make sense?”** in terms of finding, understanding and using information. The aims were to:

- Capture in detail the experience of learners as they find, process and understand information about local sources of support to manage long term conditions
- Engage with disadvantaged communities who are at higher risk of poor health
- Use this knowledge to inform development of other ALISS workstreams (Technical Architecture and Communities)
- Highlight the link between health literacy, health improvement and self management for people with long term conditions
- Develop a methodology which could be re-used by other literacy groups
- Share findings with literacy, education, health, social care and voluntary organisations
- Add to the intelligence on national approaches to health literacy.

Tutors from the City Literacy and Numeracy (CLAN) Project agreed to facilitate contact with two groups of learners in two areas of Edinburgh, Muirhouse and Wester Hailes.



*Adult learners, tutors and project team, Muirhouse, Edinburgh*

Jeni Bainbridge, a administrative assistant in Scottish Government’s Long Term Conditions Unit, helped plan three half day sessions at weekly intervals. The project team included two representatives from Long Term Conditions Alliance Scotland (LTCAS), two from the Self Management Programme of the Scottish Government (Jeni and the Self Management programme manager who was also a nurse) and an information consultant. Learners had enrolled in the class for a variety of reasons, including dyslexia, poor experiences of education and missed schooling due to poor health. The class ability in literacy and numeracy was mixed; some participants were confident readers but lacked writing skills and some were poor readers with reasonable writing skills. It was striking that despite their young age (most were in their twenties), nearly all were living with more than one long term condition, which included depression, self-harming behaviour, asthma,

epilepsy, multiple sclerosis and breast cancer. Learners were interested in finding out more about self management and agreed to participate as a learning experience.



*Adult learners, discussing support in the community*

In the first session, learners exchanged stories of living with long term conditions and the effect it had on their lives. The project was explained by showing the **"Being Patient"** video diary, which showed the member of the team visiting community centres, GP practices, libraries and looking at notice boards etc. Learners were then asked to go round their community to find support for whatever issue they chose and report back in a week.

Meantime, the team had mapped out available local support to provide a comparison with learner's findings. When learners reported back it was apparent that they had missed most local resources, which could have helped them. A shared observation was the difficulty of finding support - learners noted out of date leaflets and online information, and one reported a wasted journey to the opposite side of town due to inaccurate information.

All learners reported practical difficulties accessing local support and sometimes getting to resources presented challenges. They experienced a number of barriers such as the cost of transport, difficulty understanding maps and bus timetables. Health conditions which limited mobility, disadvantaged those who were looking for information. For example, a learner with multiple sclerosis could not

attend a specialist centre in another part of the city as she depended on a family member for transport.

Learners placed a high value on informal sources of support. A good deal of information about community resources was discovered through word of mouth. When asked, **"how did you find out about that?"** learners would often reply **"from a neighbour"**, **"from someone at the bingo"**, **"from a friend"**, **"from my auntie."** Having someone to help was important, especially to retrieve and understand information (tutors played a vital advocacy role).

Learners reported that most health care staff did not adequately address their needs and knew little about community resources. As a result, opportunities for encouraging self management were missed due to misunderstandings and there were numerous examples of people misinterpreting or mishearing health information. There were many thought-provoking conversations as the disadvantages of poor literacy became apparent. The feeling of confusion and exclusion permeated aspects of their lives such as employment, education, health, housing and family relationships. A learner, Craig, who had joined the group to improve his numeracy skills, had a condition called neurofibromatosis but had stopped attending check up appointments as they **"were a waste of time"**. He shared his experience with the group:

**“ One day... I was cleaning windows at the Astley Ainslie Hospital ... and went into one particular room where it had a coffee table that had neurological self-help groups, so great – picked it up. Found the self-help group for the Neurofibromatosis... and it was the Nf2 Association. Contacted them and then the ball started rolling. ”**



After contacting the Nf2 Association and speaking to others with the same condition, Craig was encouraged to attend a doctor who was “alarmed” that he was up ladders cleaning windows and advised him to give up his job and driving, which made a significant impact on his life. He described feeling shocked “because I knew so little about my condition”.

Learners reported that most conversations about health and wellbeing took place within families and with literacy tutors, unless there was a reason to visit their local general practice. There was agreement about the impact of poor literacy on understanding written health information – **“It’s not always that you can’t read, it’s that you can’t understand what you’ve read.”** Linda.

CLAN tutors described the ALISS Health Literacy workstream as a very useful personal learning experience and decided to include community health information as a regular learning topic. They agreed that discussing health and wellbeing in local terms was a way to promote health improvement while improving literacy and numeracy skills.

**“ ....it reinforced how difficult it is for people to access and use information and how encountering a barrier can just stop somebody dead in their tracks ”** (Tutor)

The ALISS Health Literacy workstream report<sup>20</sup> confirmed that local support may be available but is hard to find. Living with complex multiple conditions and poor literacy skills presents huge challenges for people, their families and carers. Once support is identified another hurdle is the degree of confidence required to join in - the act of **“joining in”** was a significant barrier and was particularly hard if disadvantaged by poor literacy skills, feeling unwell or depressed. It was clear from the Health Literacy workstream that a lack of connections meant that people missed support which was right on their doorstep.

<sup>20</sup> ALISS Health Literacy Report, 2010, [http://www.alliance-scotland.org.uk/download/library/lib\\_5461d6ec4ca33/](http://www.alliance-scotland.org.uk/download/library/lib_5461d6ec4ca33/)

# Professional support for ALISS

Professionals, interested in signposting people to support, were also reporting difficulty in finding information on local resources. The need to learn more about the community aspect of primary care was highlighted in Royal College of General Practitioners Scotland's report **"Time to Care, Health Inequalities, Deprivation and General Practice in Scotland."**<sup>21</sup> The report refers to the fragmentation of services and the need to have quick and easy access to local resources, a theme which was explored in more detail in an activity on community engagement and Social Prescribing Activity Report 8, GPs at the Deep End initiative.<sup>22</sup>

**"Time to Care"** noted that primary care teams are usually unaware of available activities and supports in the community as they can't find them and don't usually live in their practice areas:

**“Opportunities for anticipatory care are often fleeting and may be lost if there is not the opportunity to connect quickly with other disciplines and services that are closely linked to the practice. Practices provide contact, coverage, continuity, flexibility and coordination, and need to be recognised and supported as the hubs around which other services operate.”**

The Links Project<sup>23</sup> made reference to the nature of community connections and how signposting could link people to helpful resources. The five month project aimed to support anticipatory care and self management by improving connections and engagement between practices and the communities they serve. The project presented an opportunity to learn more about how primary care staff find, understand and use information, and in particular how they access local resources. One of the recommendations of the Links Project was that ALISS should be implemented in primary care.

Other professional support came from key directory service providers, Renfrewshire Council and Grampian Care Data, who both supplied data from their systems at the testing stage, for direct import into the ALISS Engine.

The team was therefore reassured about the benefits of creating an online system to contribute and share local information. Attention turned to what type of information ALISS would hold and, just as importantly, what it would not hold.

<sup>21</sup> Royal College of General Practitioners Scotland. 2010. Health Inequalities, Deprivation and General Practice in Scotland: RCGP Scotland Health Inequalities Short Life Working Group Report, [Online]. Edinburgh: RCGPS. [Date Accessed 03/06/15]. Available from: URL <http://www.rcgp.org.uk/policy/rcgp-policy-areas/-/media/Files/Policy/A-Z-policy/Time-to-Care-RCGP-Scotland-report-on-Health-Inequalities-2010.ashx>

<sup>22</sup> GPs at the Deep End. 2010. Deep End Report 8 Social prescribing The eighth activity of General Practitioners at the Deep End, [Online.] [Date Accessed 03/06/15]. Available from: URL [http://www.gla.ac.uk/media/media\\_179091\\_en.pdf](http://www.gla.ac.uk/media/media_179091_en.pdf)

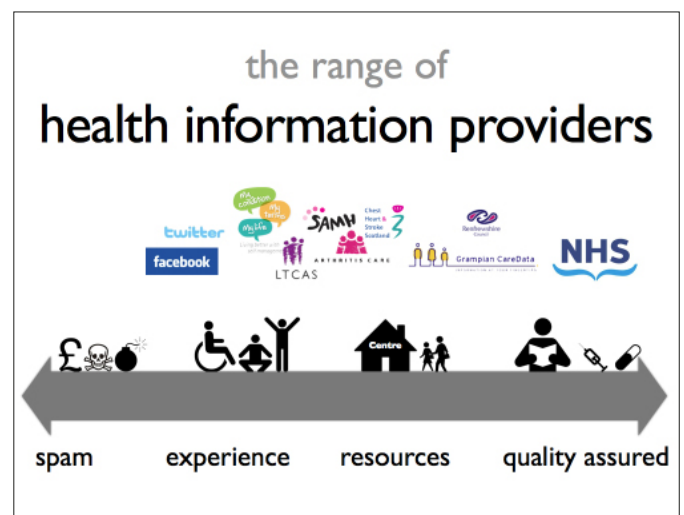
# What information will ALISS hold?

ALISS aimed to collect the sort of information that is local and personal and not clinical or condition specific, to link resources and encourage people to contribute information rather than simply consume it. There was no intention to duplicate health information, which was being produced by national and NHS Boards, such as NHS 24 and NHS Inform. However, there would be great benefits for all systems through strengthening links.

**what kind of information?**

- what is diabetes?
- what are the treatments? **quality assured**
- what do I do now?
- who can I talk to?
- what will it be like? **local & personal**
- will I cope?

The purpose of ALISS was to share people's experiences and enable self management, so the focus was on the middle range. A system of applying filters would ensure that quality assured information could be presented separately within ALISS (for organisations such as Health Boards and NHS Inform).



ALISS made a start by exploring the range of available information about health and wellbeing, which extended from dangerous to quality assured information. There was also a large range of information providers, from informal social media to statutory quality assured organisations, such as NHS Inform.

# The Open Innovation Process

## Background to Open Innovation Process (OIP)

The ALISS team was being reassured that despite living in an increasingly smart, networked environment, there was still a mismatch between providing and finding information. A huge amount of support for self management, published through posters, websites and leaflets, were not easily accessed by those who most needed them. The ALISS approach was that simply delivering an IT solution would not work. Creating the ability for citizens to generate content would co-produce a much more sustainable resource which, by its nature, would represent the diversity in our multicultural communities.

David Boyle and Michael Harris described co-production as meaning **“delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.”**<sup>24</sup> ALISS aimed to develop a system which was guided by the middle box – full co-production.

		Responsibility for design of services		
		Professionals as sole service planner	Professionals and service users/ community as co-planners	No professional input into service planning
Responsibility for delivery of services	Professionals as sole service deliverers	Traditional professional service provision	Professional service provision but users/communities involved in planning and design	Professionals as sole service deliverers
	Professionals and users/communities as co-deliverers	User co-delivery of professionally designed services	Full co-production	User/community delivery of services with little formal/ professional
	Users/communities as sole deliverers	User/community delivery of professionally planned services	User/community delivery of co-planned or co-designed services	Self-organised community provision

SOURCE: Adapted from Carnegie Trust (2006), 'Commission for Rural Community Development – Beyond Engagement and participation, user and community co-production of services.' By Tony Bovard, Carnegie Trust.

<sup>24</sup> Boyle, D. and Harris, M. 2009. [Online]. The Challenge of Co-Production: How equal partnerships between professionals and the public are crucial to improving public services London: NESTA. [Date Accessed 03/06/15]. Available from: URL <http://www.neweconomics.org/publications/challenge-co-production>

<sup>25</sup> Ali, R, Mulgan G, Sanders, B, Tucker, S. 2007. Social Innovation: what it is, why it matters and how it can be accelerated [Online]. [Date accessed 03/06/15]. Available from: URL <http://www.sbs.ox.ac.uk/ideas-impact/skoll/research/social-innovation-reports-resources/social-innovation-what-it-why-it-matters-how-it-can-accelerated>

<sup>26</sup> NESTA and the Innovation Unit. 2010. [Online]. Radical Efficiency: Different, better, lower cost public services. London: NESTA. [Date Accessed 03/06/15]. Available from: URL [http://www.nesta.org.uk/sites/default/files/radical\\_efficiency.pdf](http://www.nesta.org.uk/sites/default/files/radical_efficiency.pdf)

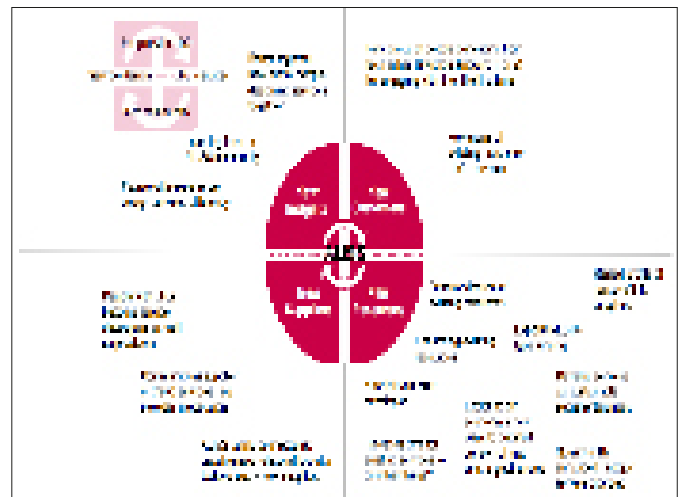
The Open Innovation Process (OIP) was inspired by papers such as Geoff Mulgan's "**Social Innovation: what it is, why it matters and how it can be accelerated**"<sup>25</sup> which stated technology should be linked to social innovation to change behaviour and that people are carriers rather than owners of ideas. It was this theme of ideas being carried, shared and worked on by others, which formed the framework for the workshops.

Inspiration also came from NESTA's Radical Efficiency,<sup>26</sup> participation in BarCamp<sup>27</sup> and Social Innovation Camp<sup>28</sup> events. (Barcamps are open, user-generated participatory events, primarily focused around technology and the web. The Social Innovation Camp model invites ideas via the web and then organises a concerted effort to build a web-based solution in a time-limited event).

Advice was sought from initiatives such as Rewired State<sup>29</sup> and futuregov<sup>30</sup>, who had experience of using social innovation methodology to redesign public services. In autumn 2009, the team met Dominic Campbell of futuregov. Dominic was interested in the ALISS proposal and put the team in contact with Snook,<sup>31</sup> two Scottish design graduates with an interest in public service design, who were commissioned to facilitate the OIP. (Dominic presented ALISS at the Harvard Kennedy business school, in 2010, as an example of innovation in Scottish Government health and public services).



Slide from Dom Campbell's presentation at Harvard Kennedy Business School, Boston<sup>32</sup>



Andy Hyde, a member of the team, mapped ALISS to the concept described in Radical Efficiency<sup>33</sup>

## Aims of the OIP

- To test the ALISS Engine (the technical software)
- To test whether the team could engage varied groups in creative and collaborative processes to develop ALISS
- To learn how to explain what ALISS was and what it could be
- To create an ALISS ecosystem.

## The ALISS OIP Process

The ALISS OIP consisted of individual conversations with people living with long term conditions, meetings and a series of three workshops across Scotland, followed by a final two day workshop. The purpose was to generate ideas, collaborate and develop the ALISS Engine. The team invited people living with long term conditions, health and social care staff, designers with a focus on public service, experts in information technology and social networking, policy, planning and providers of information. Both statutory and non-statutory sectors were represented.

<sup>27</sup> Wikipedia. 2015. BarCamp. [Online]. [Date accessed 03/06/15]. Available from: URL <http://en.wikipedia.org/wiki/BarCamp>

<sup>28</sup> Sicamp.org. 2009. Social Innovation Camp Scotland on Film. [Online]. [Date accessed 03/06/15]. Available from: URL <http://www.sicamp.org/social-innovation-camp-scotland-on-film-2/>

<sup>29</sup> Rewiredstate.org [Online]. [Date accessed 03/06/15]. Available from: URL <http://www.rewiredstate.org>

<sup>30</sup> FutureGov, Digital and Design Company for Public Services [Online]. [Date accessed 02/03/15]. Available from: URL <http://www.wearfuturegov.com/>

<sup>31</sup> Wearesnook.com. Snook. [Online]. [Date accessed 03/06/15]. Available from: URL <http://wearesnook.com/snook/>

## Preparing for the OIP

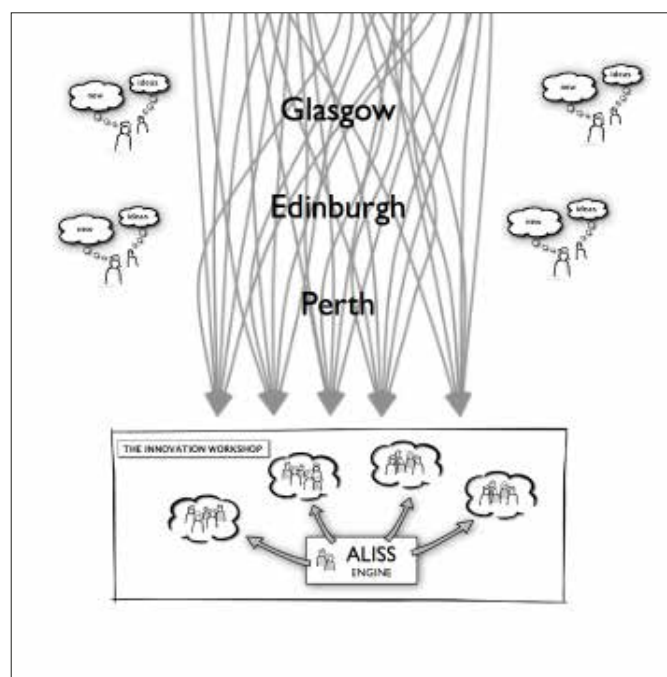
Two Scottish service designers, Sarah Drummond and Lauren Currie, were enthusiastic about the ALISS vision and had just set up Snook<sup>34</sup>, a design company. It was agreed Snook would:

- Gather insights through interviews with people living with long term conditions and providers of information
- Use these insights to produce a film to share with participants and technical developers
- Design workshop tools and materials to help generate ideas
- Plan and facilitate a series of workshops across Scotland in February and March, 2010

Snook gathered the following insights during interviews:

- People are information hubs
- Self confidence is key, family and friends don't always understand
- Things people learn about supporting themselves are not condition specific
- Activities to improve physical and mental wellbeing are not condition specific
- The support people need and want is not condition specific
- Physical and emotional support are different
- People don't want to moan
- Support and information needed is dependent on the situation you are in at the time
- We all communicate in different ways.

The OIP was to be an opportunity for people, who don't often come together, to meet and exchange ideas - people living with long term conditions, carers, designers (with a special interest in public services), experts in software development and social networking, representatives of Scottish Government, librarians, major information providers such as NHS 24 and NHS Boards, Citizens Advice Scotland, Voluntary Health Scotland. LTCAS was a great help in brokering connections with people and third sector organisations.



Workshops were organised in different parts of Scotland over the course of two months; three half day workshops at weekly intervals in Glasgow, Perth and Edinburgh, followed by two consecutive full days in Glasgow. In line with Geoff Mulgan's paper, the plan was that each workshop would develop ideas generated from the one before and groups would present their idea on the final afternoon.

<sup>32</sup> Slide from Dom Campbell, FutureGov presentation, Harvard Kennedy School, Ash Center for Democratic Governance and Innovation, March 2010; <http://www.wearefuturegov.com/>

<sup>33</sup> Nesta and the Innovation Unit, 2010; *Radical Efficiency: different, better lower cost public services*; available at [http://www.nesta.org.uk/publications/reports/assets/features/radical\\_efficiency](http://www.nesta.org.uk/publications/reports/assets/features/radical_efficiency)

<sup>34</sup> Wearesnook.com. Snook. [Online]. [Date accessed 03/06/15]. Available from: URL <http://wearesnook.com>

## Workshop 1 – Glasgow



*Jenny Dowswell, preparing for Glasgow workshop*

The vision and purpose of ALISS was introduced to 36 participants and the scene set by showing Being Patient and Snook's **"Insights"** film. Participants were asked to form groups to think in detail about their daily experience, living with a long term condition, and how their lives could be improved. Snook used design tools such as a template of a newspaper and character personas to encourage groups to make their own headlines and to ask, for example, "how would Mary use this idea?" "Who would make this idea happen?" The process produced dozens of ideas about the value of strengthening support in communities and valuable insights into what was really important to people. Participants

agreed that it was hard to find out about formal and informal support, particularly if the issue was about mental health. Stories were swapped about loneliness and also the power of "word of mouth" in finding useful support at the time that you needed it most.



*Discussions in the Glasgow workshop*

The ideas, which were carried onto the second workshop, included an idea from John, who'd had a stroke. He described feeling alone and helpless when he got home from hospital and was unable to cope with everyday things. He had returned to find bills and debt collectors at his door. John's idea was for a helper who would talk you through life with a long term condition. This idea about befriending was subsequently developed by others in a storyboard called **'My Perfect Friend'**.<sup>35</sup>

<sup>35</sup> [alissopeninnovationprocess2010.wordpress.com/ideas/](https://alissopeninnovationprocess2010.wordpress.com/ideas/). Ideas: First Things First. [Online]. [Date accessed 03/06/15]. Available from: URL <https://alissopeninnovationprocess2010.wordpress.com/ideas/>

## Workshop 2 - Edinburgh

The second workshop was in Edinburgh, where Carrie Bishop of FutureGov, joined twenty-six participants. Participants were asked to think about what they could share if their ideas were real, for instance their time, skills, knowledge, experience, advice, space. Storyboards were used to illustrate the steps involved in each idea and participants were shown how to blueprint.

The second part of the session was allocated to linking their ideas to ALISS, for instance, how they could add their knowledge of support and how ALISS could support them. One of the positive

surprises was the willingness of participants to work on ideas developed by others.

There was support for finding ways to share information and a consensus that online searches were often a waste of time. However, there was also a discussion about the lack of detail about what ALISS would look like. At this stage the technology was still in development and so it was difficult to explain what the finished product would look like, people were being asked to contribute to the creation of a national tool which did not yet exist. This was a salutary reminder of the challenges of the early stage of co-design, inherent in the innovation process.

## Workshop 3 - Perth

The third workshop took place on a day of heavy snowfall. The team were delighted that twenty-five people made it in white-out conditions to attend. Participants included the Airlie Silver Surfers, a group from Angus, who run a cyber cafe and support beginners to use computers, for instance helping people to use Skype to keep in touch with relatives abroad.



*Airlie Silver Surfers*

The Perth workshop repeated the format of carrying ideas from the previous two workshops, and participants came up with additional ideas such as:

- The Magic Phone Number, which would provide a menu of options including **“Can I get help with managing my long term condition?”**
- The Get Moving Group, providing information about local support for self management, with opportunities for people to develop and share their skills with others
- Kindred Spirit, to provide support for people to make contact with others in a similar situation
- Encouraging people back into activities they previously enjoyed.

The most significant difference in this workshop was the contrast between rural and urban areas as participants reflected **“we know everyone and everything that’s happening.”** The group agreed that ALISS had potential to work particularly well in smaller communities.

Everyone was sent home in the snow with a slice of cake brought along by a participant, Alec, who was a baker.



36 Andy Hyde. 2010. The ALISS Engine [Online]. [Date Accessed 03/06/15]. Available from: <http://vimeo.com/11986849>

37 Slideshare.net. Introduction to the ALISS Project. [Online]. [Date accessed 03/06/15]. Available from: URL <http://www.slideshare.net/picah/introduction-to-the-aliss-project>

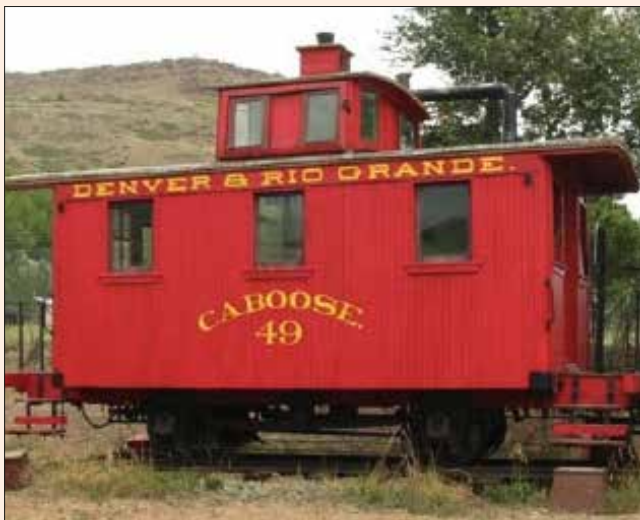


## Glasgow - the final two day workshop

The final part of the innovation process was a two day event which took place on a Thursday and Friday in March 2010 at LTCAS's large offices in Glasgow. Consecutive days were chosen to keep people motivated and interested, as per the BarCamp method. Breaks were planned so participants could take a breather from the intensity of small groups, network, listen to other interesting presentations, go for a stroll or see a demonstration of the ALISS working model.

Behind the scenes, ALISS software had been developed with reference to feedback from workshops. Questions and ideas were shared with the software developer, including queries about quality assurance, how to open an ALISS account, filtering information, the possibility of having an ALISS search box on third party websites etc. Responses were prepared and a working model<sup>36</sup> was developed in time for the final two-day workshop so that everyone could see how ALISS would work (see from slide 45 in this presentation)<sup>37</sup>

At the heart of ALISS technology was the ALISS Engine. The 'viewing car' (the platform where the technical team "hung out") was nicknamed the Caboose. 'Excursions' on the Caboose were offered throughout the two days.



The ALISS Caboose - Rio Grande<sup>38</sup>

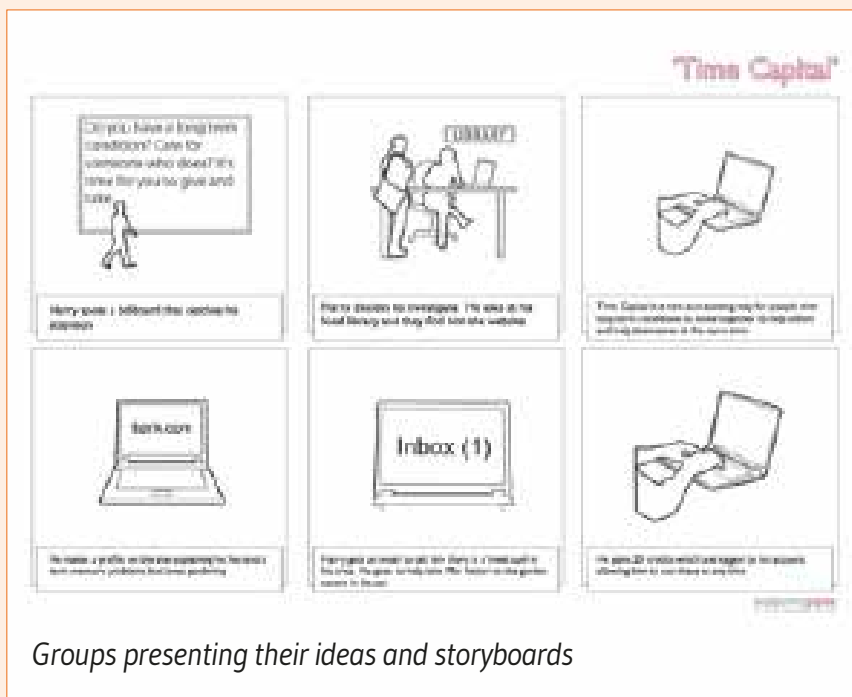
Almost sixty people attended the final event; a lively mix of people living with long term conditions, carers, designers, software developers, and information and service providers. Mentors with particular expertise included James Munro, of Patient Opinion, AnneMarie Cunningham, a GP and Clinical Lecturer from Cardiff with experience of social media, Katie Brown from MIND in Leeds and Gillian Easson from Nesta's Age Unlimited Programme, Gavin Venters from Scotland Health on the Web. The team were delighted that Lauren Currie, a Director of SNOOK, invited her mother Christine, an experienced business and marketing professional, to help groups develop their plans and think about ways to make it happen.



After a brief introduction and explanation of the rules of engagement<sup>39</sup>, participants formed groups which were expertly facilitated by the 4th year students from Glasgow School of Art. The students helped move an outline idea (or mix of ideas) towards a service proposal and also photographed and filmed the event.

<sup>38</sup> Image courtesy of the Colorado Railroad Museum, [Online] [Date Accessed 05/05/14] <http://coloradorailroadmuseum.org/museum-home/cabooses/>

<sup>39</sup> How the ALISS innovation process will work - slideshare [Date Accessed] [04/02/15] <http://www.slideshare.net/pashe/how-the-aliss-innovation-workshop-will-work>



Groups presenting their ideas and storyboards

A range of diverse ideas emerged over the two days, such as time banking, buddy networks, storytelling as an underused business tool and developing information services for people with a new diagnosis. Each group was given suggestions on ways to bring their idea to life, for example, how to do an elevator pitch, using templates for story boarding, business plans and future visioning. An important purpose of the process was to make ALISS real and so “excursions” in the Caboose (represented by a large Mac computer) were organised so people could see how ALISS worked, and how it could support their idea.

The link between each group’s idea and technical development, was symbolised using balls of wool. Each group workspace was connected to the Caboose by a long length of different coloured wool. Requests to the Caboose were written on small cards, which were attached along the lengths of wool. Example queries included: **“how will staff access ALISS?”**, **“Will resources in ALISS be seen by everyone?”**, **“Could ALISS handle one off events?”**, **“Who can get an account?”**



Sending queries to the ALISS Engine

The working model<sup>40</sup> was critical in the OIP. Demonstrating the model made ALISS real, this was the first time people could see how crowd-sourcing information could benefit all. The demonstrations triggered queries for the technical crew who considered requests for additional functions for ALISS.

40 ALISS Working model developed by Derek Hay [Date accessed 09/06/15] Available from: URL <https://vimeo.com/11986849>

41 Alissopeninnovationprocess2010.wordpress.com. Ideas. [Online]. [Date accessed 03/06/15]. Available from: URL <https://alissopeninnovationprocess2010.wordpress.com/ideas/>

42 Alissopeninnovationprocess2010.wordpress.com. People Helping People. [Online]. [Date accessed 03/06/15]. Available from: URL <https://alissopeninnovationprocess2010.wordpress.com/ideas/people-helping-people/>

## Results of the Open Innovation Process

During the two days, there were conversations about quality assurance, the role of the third sector, connected communities, siloed databases, pulling and pushing information, using twitter, ecosystems, apps and widgets, signposting and the nature of assets. The key themes which emerged were:

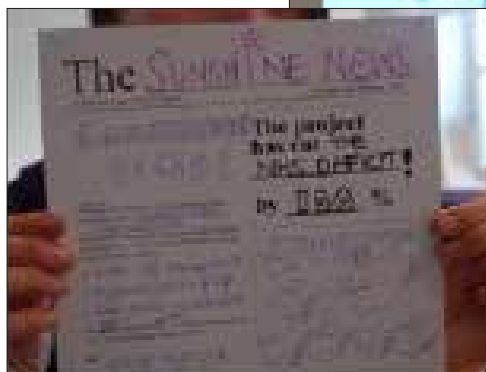
- Loneliness and social isolation. People often wanted to connect to other people and not necessarily local groups and organisations, they were not just looking for lists of services
- People find non-quality-assured support and information very useful and comforting (especially local information)
- What happens after being given a diagnosis
- Most people and staff found seeking support by searching paper lists, directories and websites frustrating and time-consuming
- Participants confirmed that the right support can be there but it is hard to find
- Many professionals would prefer filtered (smaller) collection of information
- Technology is needed to connect disparate pieces of data to make support easy to find
- Managing online and offline information is challenging
- The Engine could be a vehicle for helping people to get online
- ALISS could provide a means for organisations without websites to have an online presence.

The feeling of overwhelming confusion and shock after being given a diagnosis was a theme that occurred at every stage of the process. There were accounts of not knowing what to do next, feeling isolated and sudden challenges with everyday life tasks. It was often mentioned that there was enough medical support and resources at point of diagnosis (in the doctors surgery or at the hospital) but often the kind of support that was needed was another person, someone

who could tell you what it is like to live with the condition and help you with all the 'small' things that make life easier. A participant, who had been diagnosed with an acquired brain injury, described going home alone after being in hospital for four months, living on takeaways feeling very low. She said, **"I don't just want to exist, I want a life of quality."** One of the ideas - First Things First emerged from this theme about the immediate period after a diagnosis.

After intensive small group work, six ideas were presented to the whole group:<sup>41</sup>

- People Helping People<sup>42</sup> (access to support opportunities that already exist, but are poorly connected, allowing people with similar conditions and experiences to support each other)
- It's about time<sup>43</sup> (loneliness and social isolation, small connections make a difference).
- Plugged In<sup>44</sup> (ALISS as a "socket" for connecting information and developing idea of people as information hubs)
- First things First<sup>45</sup> (guide for someone newly diagnosed with a long term condition)
- Inca<sup>46</sup> (peer to peer bookmarking - ALISS providing relevant information at the right time)
- REACH (ALISS reaching out to people living with long term conditions).



*The REACH team presents their idea  
Using Snook's tools to generate ideas*

<sup>43</sup> [alissopeninnovationprocess2010.wordpress.com. It's about Time. \[Online\]. \[Date accessed 03/06/15\]. Available from: URL https://alissopeninnovationprocess2010.wordpress.com/ideas/its-about-time/](https://alissopeninnovationprocess2010.wordpress.com/ideas/its-about-time/)

<sup>44</sup> [alissopeninnovationprocess2010.wordpress.com. Plugged In \[Online\]. \[Date accessed 03/06/15\]. Available from: URL https://alissopeninnovationprocess2010.wordpress.com/ideas/plugged-in/](https://alissopeninnovationprocess2010.wordpress.com/ideas/plugged-in/)

<sup>45</sup> [alissopeninnovationprocess2010.wordpress.com. Ideas: First Things First. \[Online\]. \[Date accessed 03/06/15\]. Available from: URL https://alissopeninnovationprocess2010.wordpress.com/ideas/first-things-first/](https://alissopeninnovationprocess2010.wordpress.com/ideas/first-things-first/)

<sup>46</sup> [alissopeninnovationprocess2010.wordpress.com. INCA. \[Online\]. \[Date accessed 03/06/15\]. Available from: URL https://alissopeninnovationprocess2010.wordpress.com/ideas/inca/](https://alissopeninnovationprocess2010.wordpress.com/ideas/inca/)

## Did we achieve the aims of the OIP?<sup>47</sup>

The aims of the OIP process were to:

- Test the ALISS Engine (technical software)
- Test whether the team could engage groups in creative and collaborative processes to develop ALISS
- Learn how to explain what ALISS was and what it could be
- Create an ALISS ecosystem.

## Test the ALISS Engine

The ideas from the workshops were considered by the Caboose crew, and their verdict was that the structure of the Engine would cope with the theme of some participants being interested in finding people rather than activities and organisations. Software developers agreed that this would not break the technical conceptual structure, as the meaning of 'resources' could embrace people too.

Test whether we could engage varied groups in creative and collaborative processes to develop ALISS

Some people were perplexed with the unfamiliar creative process, but once they were used to it most took to it enthusiastically. People commented that they were used to being consulted about, but not to contributing to early development of projects and products.

Allowing adequate time in workshops for developing ideas was challenging. One facilitator remarked on the tendency of some participants to prefer to carry on talking about a problem while he wanted to progress towards creating a solution. Another group found it hard to think beyond improving the way they already worked until they were given a 'ticket to the future', which triggered a shower of ideas.



*Glasgow School of Art Service Designers*

Participants took to service-design techniques, all materials were effective but light-hearted, the ease of understanding and fun contributed to creativity, while expert facilitation was reassuring (this was particularly important when using unfamiliar tools such as personas, storyboards and templates). One of the design students, James Porteous wrote about his experience.

**“ From a personal perspective, it was an eye-opening experience ... I enjoyed seeing people grasp the concepts I work with in my uni coursework... it was incredibly validating to see that design process can work in real situations, with real people, who have real problems.... This workshop made me believe in design, my career, and that given the opportunity, people can achieve change for the better. ”**

Other important considerations emerged through the OIP process, such as participants' views on ownership of ideas, whether they would be prepared to 'pass and receive the baton' and work collaboratively across the life-cycle of ALISS development.

47 Alissopennovationprocess2010.wordpress.com. Innovation Camp: What We Learnt from it All. [Online]. [Date accessed 03/06/15]. Available from: URL: <https://alissopennovationprocess2010.wordpress.com/innovation-camp/what-we-learnt-from-it-all/>

**“It worked well. Everyone engaged in the process, and it was very interesting, and it felt like the group accomplished something useful.”**

**“Overall, all enjoyed working together and coming up with a fun service. Was really nice to see all the smiles on peoples’ faces.”**

**“It has to be the way forward in getting information on any long term condition”**

### **Did we learn how to explain what ALISS was and what it could be?**

“What is ALISS?” was a recurring question. A slide of the Lion of Gripsholm Castle provided an amusing analogy to explain the challenge of constructing something, like ALISS, which was hard to visualise. In the 18th century, King Frederick of Sweden was gifted a lion, which he wanted stuffed, however the taxidermist had never seen a lion and so had to use his imagination and put together the components as best he could (the very strange looking lion can be seen in Gripsholm Castle, Sweden).

The ALISS team were doing the same, constructing technical software and creating an ecosystem, not knowing what the finished product would look like. It was thought that this was probably not because the concept was complicated, but because it was about developing infrastructure.



*The King of Sweden's Lion*

The OIP was helpful in collectively arriving at an agreement that ALISS:

- Was a receptacle (a digital place to put and find things)
- Would have a search widget and a tool for identifying (tagging) resources, and a way to apply key words to resources
- Is not a database, or a search Engine, or a website, it is an ‘open’ core for collaborative development and combining directories of resources
- Is a software development, but also a platform for innovation and other services.

### **ALISS as an ecosystem**

The ALISS project set out to recognise that every individual is both a source and consumer of information. The intention was to create an ecosystem where people living with long term conditions and those providing resources for self management could manage linked resources and create new services that drew from a new national set of data. The mix of technology and social processes worked well during the OIP, the process contributed to creating a new, wide-ranging, multidisciplinary community of enthusiasts who were keen to contribute to the future development of ALISS. This ecosystem gained strength as the purpose and the huge potential of the system gradually became clearer.

### **Were there any surprises?**

The biggest surprise was the emphasis people placed on finding people as well as activities or clubs, etc. Their first objective was to find a kindred spirit, perhaps someone who had been through the same experience, and who could act as a guide to opportunities and sources of help.

Post-diagnosis was a key stage when many participants felt completely lost, especially if there was a delay while waiting on results or to see specialists. The distinction about this period was about not knowing what to do next, feeling isolated and often being unable to manage

everyday life tasks. There was also an emphasis on the value of exchange - people did not see themselves as mere consumers of things aimed at helping them live well, and were keen to work on proposals which were based on the principle that everyone has something to contribute. The 'It's About Time' proposal is an example of this. Other surprises included:

- During the two day innovation workshop, there was a dip in energy levels late on the Thursday afternoon (the first day) but a miraculous Friday morning recovery
- Unexpected combinations of people working productively together
- The work before, during and after the OIP divided into three more or less equal commitments – the OIP generated an immense amount of material which took more time than expected to process
- Participants offering feedback said they wanted to remain involved, and suggested that they would like to run ALISS workshops locally
- People found it enjoyable.



Thanks to advice from LTCAS, events were designed to suit people's limited stamina, although this was sometimes a challenge:

**“ I think it went very well and everyone had their say but I found it a long day as I tire after my stroke. ”**

The OIP helped to define the technology requirements and created a new, wide-ranging, multidisciplinary community who placed a high value on developing something useful for the public good.

# Assets and mapping them

The early development of the ALISS project coincided with a growing interest in how assets-based approaches could improve health and well-being which was being championed by Sir Harry Burns, the Chief Medical Officer for Scotland. In his 2008 Annual Report **“Health in Scotland 2008 Shedding Light on Hidden Epidemics<sup>48</sup>”**, Sir Harry described the importance of shifting from a deficit model (centred on what people cannot do) to one which aimed to increase the resilience of individuals and communities by identifying what they could do – by recognising their assets. This had particular relevance for addressing the poor health experienced by many people living in deprived areas of Scotland. Sir Harry suggested that this shift would require a change in the dynamics between service providers and service users and that improving health **“requires attention to the social fabric of our communities to ensure people have a positive environment in which to take decisions about their health.”** The **“social fabric of our communities”** was exactly what the ALISS system was being developed to support.



This reference to making connections in communities was echoed in the Marmot Review – Fair Society Healthy Lives (2010) which stated: **“Effective local delivery requires effective participatory decision making at local levels. This can only happen by empowering individuals and local communities.”<sup>49</sup>**

Health and social care systems across the world were exploring assets-based approaches, the difference now was that we had the web at our fingertips and so it was easier than ever to share and distribute information - fast. However despite improved connectivity and interest in assets across public services, it seemed hard to translate the interest into activity, the connections between asset mapping and opportunities for action needed to be identified.

## “What Keeps You Well?”

The team arranged asset-mapping workshops across Scotland in various contexts, for example primary care teams and community organisations. A workshop structure was developed where people could share stories and experiences, and use a map or drawing to identify resources which could then be loaded into ALISS. Workshops started with the simple question **“what keeps you well?”** People suggested their personal assets as well as places (such as allotments) and services such as self management programmes. The ALISS team had an early success with a group in south Edinburgh, when a participant drew a line down the centre of the paper to represent Leith Walk (a long street in Edinburgh), people added

<sup>48</sup> Scottish Government. 2009. Chief Medical Officer Annual Report 2009 Health in Scotland 2008: Shedding Light on Hidden Epidemics, [Online]. Edinburgh: Scottish Government. [Date Accessed 03/06/15]. Available from: URL <http://www.gov.scot/Publications/2009/12/16103619/0>

<sup>49</sup> Marmot M. 2010. The Marmot Review: Fair Society Health Lives: Strategic Review of Health Inequalities in England post 2010 [Online]. [Date Accessed 03/06/15]. Available from: URL <http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review>

resources they knew about, which were then indexed in ALISS.

Meanwhile, ALISS technology was being developed to allow people and organisations to quickly translate discoveries into index records, making them available to others for the first time. The advantages of this process were:

- Bringing people together to develop local opportunities
- Contribution of their discoveries to ALISS a national (local) online resource
- Improved data for existing information services (such as NHS Inform)
- Opportunities to build new information services.



## Asset Mapping in A Box (AMIAB)

Asset Mapping in A Box emerged from these workshops - a process designed to gather and publish information about community assets, using the collective experiences of interested agencies around Scotland. AMIAB was a set of processes and tools to:

- Explain the benefits of identifying and collecting assets
- Understand what is required to make a local assets based approach work
- Develop asset mapping events
- Gather, publish and share discoveries at a local and national level
- Explore ways to enhance existing information services and to build new ones
- Develop opportunities to bring local people together and add their contributions to a national online resource
- Share and improve data for existing information services (such as NHS Inform)
- Improve efficiency as siloed information becomes joined up
- Develop new information services not yet thought about.





# Communities

## ALISS and the Curriculum for Excellence

It was becoming clear that it was possible to develop technology to link existing databases, make information more findable and so address the problem of hundreds of siloed directories. However, a sustainable method of local information gathering was needed to make it easy for the community to share and contribute their knowledge of local resources.

Peter Ashe, a member of the ALISS team, came up with the intriguing idea that school children could be hunter gatherers of local assets, likening this activity to a school trip to a museum where pupils would take a note of exhibits and write up their observations once back in class. ALISS hunter-gatherers could do the same; spot local assets, discuss them in class and add them to ALISS during their IT lesson. This could be an innovative way to introduce young people to an understanding of living well and about the sort of behaviours which may protect their health. Pupils collecting local assets as part of the school curriculum, would find out more about their area, learn about local activities, contribute to the community and make subtle connections between social and digital processes. This was an example of offering ALISS to different communities of interest in terms that made sense to them, so they were not 'doing someone else's project'.

ALISS activities were mapped on to Scottish Government's Curriculum for Excellence (CfE). Three areas in the list of Experience and Outcomes<sup>50</sup> chimed well with ALISS's ambitions: Health and Wellbeing, Social Sciences and Technologies. Using this framework, students could be guided to:

- Find out about local community groups and activities (Social Studies; Technology)
- Consider what these involve and the contribution they make (Health and Well-Being, Social Studies)
- Consider how they work as organisations (Social Studies)
- Consider the choices people make about joining in and benefits of engagement (Health and Well-Being)
- Make a pod or videocast of an interview with someone with experience of living with a long term condition (Technology).

Mr Alec Morris, Head Teacher of Trinity Academy, a large secondary school in Edinburgh, was briefed about the long term aims of ALISS and was keen for pupils to contribute to its development. Mr Morris predicted that, through time, schools contributing to the health of their communities in a way which was consistent with timetables, had potential to **"become the way things are done."** It was intended that the involvement with schools would take place over several phases, to match stages of technical development. At this early phase, the ALISS Engine was not yet fully developed and so the first step was to introduce the idea of the school as a connecting hub in the community and raise awareness of pupils and staff of health and wellbeing, long term conditions and self management. The Self Management Programme in Scottish Government was fortunate to be supported by a temporary administrator, Jenny Dowswell, who was a qualified teacher. Jenny was keen to be involved and it was negotiated that two hours per week would be dedicated to the Curriculum for Excellence stream.

50 Education Scotland; Curriculum Areas; [Online] [Date accessed 01 05 15] Available from URL: <http://www.education.scotland.gov.uk/learningandteaching/curriculumareas/index.asp>



*Trinity Academy Senior Pupils in the ALISS project*

The lead teacher for Health and Wellbeing helped set up the project and four senior pupils volunteered to take part. The group decided to develop a lesson plan, about health and communities, which they would present to junior pupils. The focus would be self management of long term conditions and accessing support. Jenny and the pupils co-produced the plan, exercises and materials which the pupils then delivered in a series of sessions, across their year group. The Trinity Academy team described their work with ALISS as a **"truly collaborative project"** which was **"very worthwhile"**. The lesson plan was well-received by Mr Morris and his staff, and was rolled out across the whole school during 2011 as part of their Personal, Social and Health Education programme.

The pupils entered their ALISS lesson plan in a European School Partnership Programme competition, **"Comenius – Our Healthy Futures"** and were thrilled to be selected to present their project at a conference in Germany. Students

presented their findings at the University of Applied Sciences in Bremen, to an invited audience of staff and students from Sweden, Holland, Germany and Scotland. The pupils had a fantastic week staying with local families and following this triumph, Trinity Academy were awarded further funding on the theme of active citizenship, **"Can We Make a Difference?"** to explore problems in their local community and research methods to make improvements.

Despite being resourced for just two hours per week for five months this workstream had a big impact and highlighted the benefits of joint-working between health services and schools. It was also a reminder of the benefit of taking a long view and framing ALISS in terms that made sense to other communities, in their context and constraints.

## The Boys' Brigade

Another contribution to the ALISS Communities workstream was a complimentary project which was set up alongside the Trinity Academy Curriculum and Excellence stream. This was with one of Scotland's largest youth groups, the Boys' Brigade Scotland (BBs) and was also led by Jenny Dowswell. This initiative shared the aim of developing learning experiences for children and young people. The purpose of the project was to create an 'educational toolkit' which could be used by BB leaders in a 4-5 week Health Programme. The toolkit<sup>51</sup> provided a resource for teachers and other youth organisations to generate discussion about health literacy, long term conditions and self management.

<sup>51</sup> The Boys' Brigade "Yes I Can" Long Term Ambitions, Resource Materials on the Self Management of Long Term Conditions For Young People; LTCAS, The Boys' Brigade, Scottish Government [http://www.alliance-scotland.org.uk/download/library/lib\\_565edcd0a0769/](http://www.alliance-scotland.org.uk/download/library/lib_565edcd0a0769/)

# ALISS Technical Development

## The changing nature of the web

The design of directory services was based upon an assumption that people will go to a site to search for information. However, new frames of reference were rapidly becoming available. There was a move beyond a web of pages, towards an interconnected web of people and data. This made it possible to access information through multiple channels to multiple devices without the need to search in the traditional way. The social web, for example Facebook and Twitter, was providing new ways for people to share experiences, recommend resources, connect with and support each other. Signposting, pointing people to resources, was becoming as important as an ability to find them and it was clear that future digital infrastructures would have to allow people to find information in a way that suited them, which would not necessarily be via a search box.

The ALISS team noted that the web landscape had two major characteristics - a multitude of informal original source-providers with little knowledge of how the web works but who wish to publish their information because it is useful, and a range of institutional information providers who work hard to provide lists of established groups, constantly struggling to quality assure and keep databases up to date. Both characteristics appeared to be rapidly declining in value as systems for linked and structured data were emerging.

There was a place for technology which could gather personal and community assets and make them available to all, immediately, on the web. A technical solution to linking data in a

way that promoted living well and which “**crowd sourced**” content did not exist, and so the ALISS proposal was both ambitious and innovative.

## Purpose and aims of technical architecture

The purpose of ALISS technical architecture was to develop an infrastructure which would be a ‘delivery system’ in the most general sense: delivering a service rather than simply bits of data; connecting people as well as resources; allowing people to contribute and share information rather than simply consume it. The aims were to:

- Enable people with long term conditions and others to disseminate information and link with others seeking similar services
- Provide access to information which is not easily found in Google
- Provide a filter so that organisations can have their own “view” / collection in ALISS
- Provide a platform for sharing best practice and experiences in self management support
- Develop a prototype to “harvest”, “tag” and make available information about resources to support self management in communities
- Produce a means to encourage development of local resource directories which can be customised (for instance organisations may choose to have their own look and content)
- Provide fast access to local information and support which does not already exist

- Develop relationships with existing information providers and collators (develop an ecosystem)
- Provide an electronic means for users and providers to collect data, identify gaps in self management support (for instance tracking failed searches, heatmaps), which would be useful for local planners, Community Health Partnerships and service providers.

The starting point was to address the following challenges:

## Reusability of data

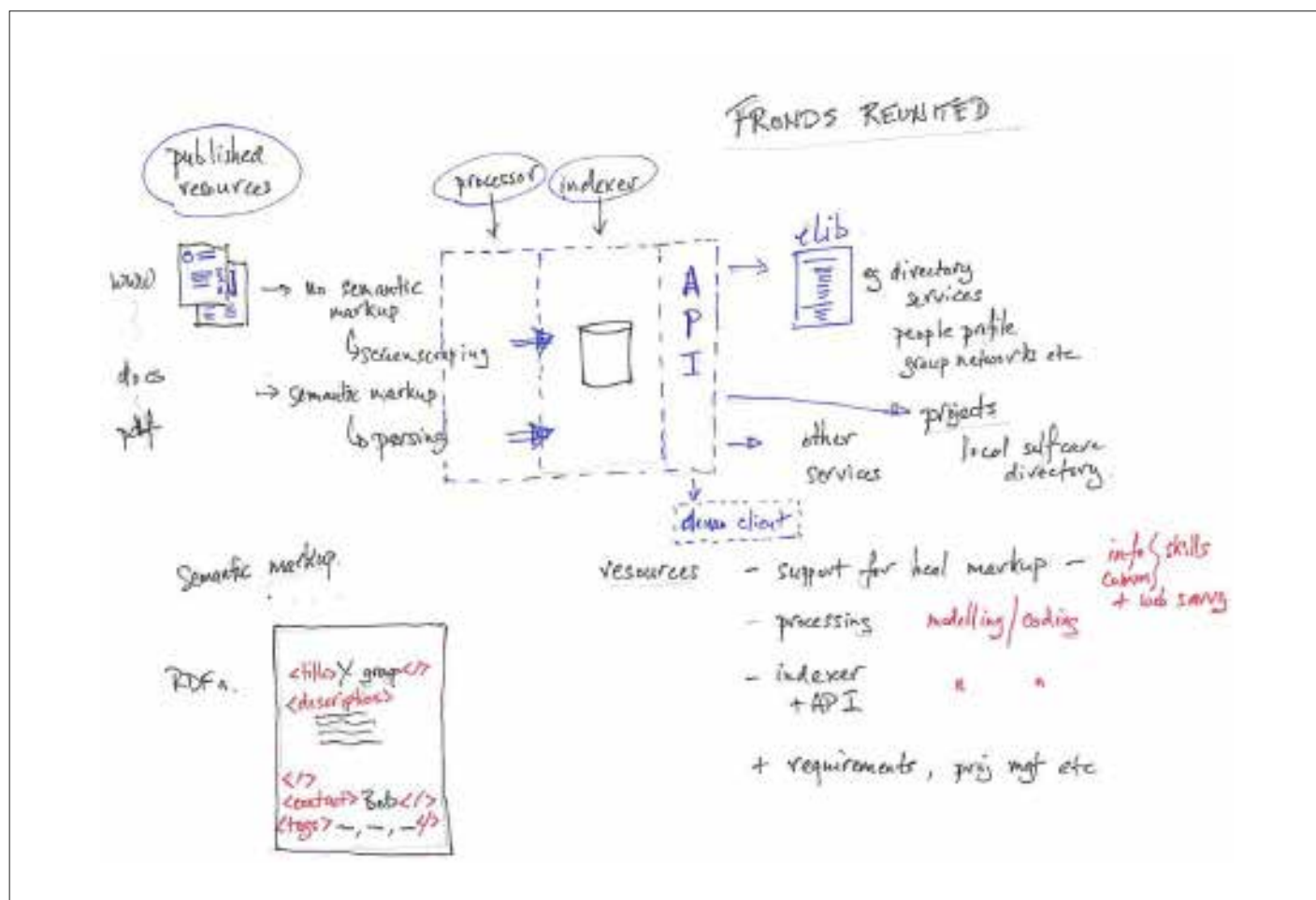
Directory services traditionally create silos of information that require users to visit them to access data. This useful, locked up information is usually hidden from major search engines and therefore has a declining value.

## Creating opportunities to co-design ALISS

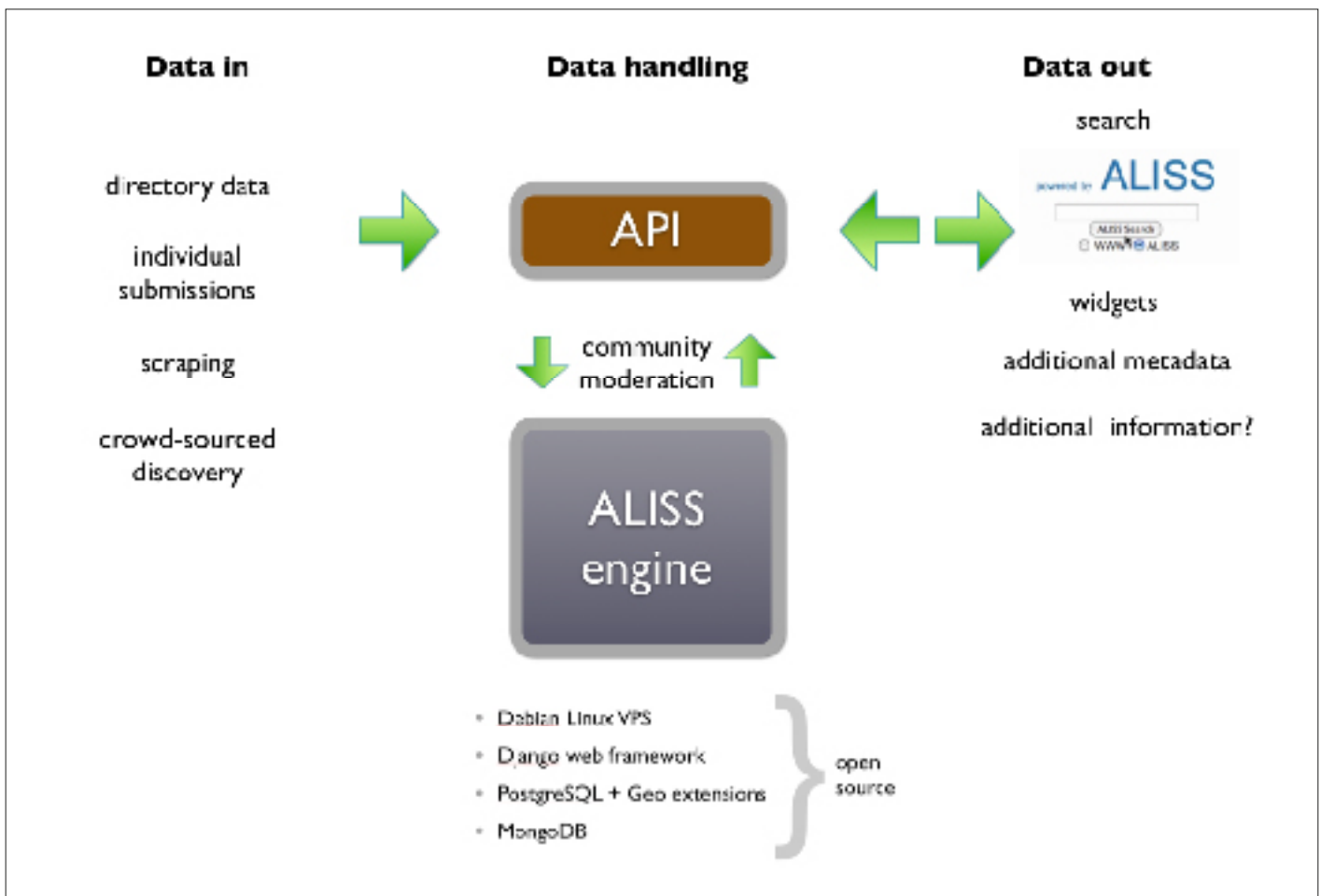
Developing a tool about support for self management would be richer and more useful if it allowed contribution from users.

## Keeping data current

Maintaining accurate records on local resources is a full-time job; services have to contact organisations, log activities, update records and supply information in a meaningful way to people who may not be used to deep searching on the web. But people and organisations are busy, providing their service has a higher priority than keeping information updated.



Fronds Reunited – the original plan for ALISS



*The proposed architecture of the Engine:*

## Reflecting smaller and less visible services

Useful support for people with long term conditions may be provided on a small scale, for instance just one person organising a walking group, or a carer support network at a church hall. This is difficult to discover and unlikely to have an extensive web presence. Useful online content is often ephemeral or produced by people with little knowledge of the web and search engine optimisation. This type of content is likely to be ignored by more formal directory services and is poorly indexed in search engines.

## Considerations for implementation:

- Social components should both define the context of ALISS and be a vital part of the project itself
- The architecture must take account of multiple, unpredictable sources of data, and multiple, unpredictable uses of the data
- To ensure sustainability and repurposing of software, the 'ALISS Engine', (the central processing component), must be open-ended and flexible, therefore a blueprint rather than a one-off design was required.

## Plan for ALISS technical development

In late 2008 a plan, Fronds Reunited (sketched out on a café napkin) described the three components of ALISS development:

1. Information capture.
2. Processing into a sustainable resource.
3. Presentation via client systems to users.

## How ALISS would make information more findable

The plan was to develop a very simple core data model; when a resource was added there would be a link to a URL if it was web-based, some tags and a text description, along with basic metadata recording who added it and when. That resource could then have any number of curations layered on top. A curation could also have tags and a text description, and hold any structured data a user wanted to add and all this would be combined in the index. This would improve findability of resources, as users could identify resources that might be useful to their community of interest.

## Data in

- Taking in links to existing data in larger amounts
- Working with existing directory owners
- People can submit data themselves - e.g. a web form on a charity site or a form to fill in at the library/community centre - just a link, a short description, location and tags
- Links to new individual resources, sites that haven't been picked up by larger directories (e.g. events, tweets, pictures, people, services)
- Draw information directly from sites
- Sprints and community sourcing - developing online tools and processes that enable resource discovery and submission.

## Data Handling

The Engine was described as a processor, or a link, and a conduit, which did not need to be a database. The Engine would pull data in, processing what it needs, passing on content untouched if required. This would need management of diverse data structures which suggested the use of a 'document-oriented' or 'schema-less' database as the main content store. This allows flexibility to add or remove data as required, to repeat fields if needed, have nesting of content to arbitrary levels, and generally not worry about having to have a 'kitchen sink' schema.

## Identifiers

- Use resources with stable URIs from other national systems, for example activescotland.org.uk with its database of facilities and groups
- Provide a stable ALISS URI to resources that may be hard to find online, or are liable to have ephemeral URLs of their own.

## Moderation

- The ALISS engine aimed to make information more findable not act as a quality filter, however, moderation and flagging mechanisms would be developed to help make information relevant.

## Data out

API Key features:

- Support a reporting (feedback) mechanism, so that resources that are considered harmful or inappropriate can be reviewed
- Include a method of versioning, and allowing different levels of detail in the data returned.

## Additional (sets of) metadata

A partner directory service could add its own curated (assured) structured metadata to a resource, manage that metadata, and retrieve

it via the API. A partner service could query the Engine for any resources relating to 'arthritis' which also have attached metadata belonging to that service, therefore the service effectively has its own data within the Engine, collecting it and managing it, while publishing it to the world.

## Search

A search functionality would be built to allow existing services to query the Engine either integrated with their own search or as a 'powered by ALISS' search box option. The added value is that they could return information that is related to the original search, drawing from a much larger body of information that their own database might contain. For information providers such as libraries this would reduce the number of places that people have to search.

Providing additional information could be a powerful added value to include quality assured information about conditions along with self management activity information, for example a third sector site for cardiac rehabilitation could deliver quality assured heart condition information derived from NHS 24.

Derek Hoy explained this in a series of blogs, which described ALISS indexing:

**“ We mentioned the idea of having additional indexing layers over the data store. This will have two benefits: it helps us meet diverse and unpredictable needs of users, and it helps the Engine provide added-value for its providers and users. Let's take the first benefit. I may have a LTC with a medical basis, but I might also be lonely as a result of my inability to get about, or pain I experience, or whatever. How will a system know that my**

**interest in resources relating to arthritis might include groups which would help me meet people and manage my feelings of loneliness? It is a huge job to expect information providers to consider all possible interests in what they provide. So much of this depends on the context of the information user. ALISS could provide an indexing layer which would connect categories, taking into account some attributes of the person making the query, and based most likely on the experience of communities of people with the same LTC who can make the connections for us. We can order categories into hierarchies, so that searches for something general will include things that are tagged with more specific categories, and vice versa. ”**

## Widgets

One of the areas of interest was to use widgets to deliver additional layers of information. For example comments about self management classes, tweets.

## The ALISS Engine as part of a linked data ecosystem

The ALISS Engine could be a central hub of a linked data ecosystem, using resources with stable URIs from other national systems,

providing a stable ALISS URI to resources that may be hard to find online, or are liable to have ephemeral URLs of their own. It would also be possible to link resources in useful ways, for example linking a local exercise class with user experience of the class on an online forum.

Software development was separated into two phases. The first phase of the project was to gain consensus on the meaning of the ALISS architecture and then describe it for a wider audience. By working with the project team and key stakeholders, ideas were incorporated into the vision for the ALISS Engine. The steps in Phase 1 were:

- Develop a central web presence for ALISS with networking, blogging and aggregating capabilities
- Use the website to gather structured feedback and comment from key stakeholders
- Develop the architectural model and create an interactive multimedia presentation to demonstrate a number of worked examples showing how information contributions can be created, captured, added to the Engine, processed and ultimately how they might be presented to the community
- Share the presentation and related resources with the ALISS community for demonstration and discussion then refine requirements.

Phase 1 of the project required attention to the social components and 'harvesting' processes, to ensure that providers of information would buy in to the project and contribute to architecture. This was essential to encourage interest in using ALISS in the future. It was predicted that providers would range from large organisations that could modify their content to feed ALISS, to small groups that would need technical help to become involved and projects which might spring up round the provision of resource data specifically for ALISS. Examples of large providers were two key directory services providers - Renfrewshire Libraries and Grampian Care Data who provided information about local health services, social services, community services,

organisations and groups. Both supplied data from their systems which was imported directly into the ALISS Engine.

Phase 2 tested the ALISS Engine against ideas for services, gathered through the OIP.

There were two short periods of software development, the first started in September 2009 and the second in November 2010. Development was completed in March 2010 and the working model was running by March 2011. The software was developed in just a few months, the majority of time was spent on procurement and business processes.

## Developing ALISS in open source

ALISS was developed using open source software, which was increasingly being recognised by governments as being a sustainable approach, which could attract top class developers and avoid tying national systems into inflexible and expensive contracts. Both documentation and code was published in the Github repository and descriptions of the trial processes and recommendations for future operational aspects of deploying the Engine were presented in the form of blog posts, 'how-to' guides, presentations and other formats.

Developing ALISS in open source had the following benefits:

- The software was available to use at no cost
- The software was high quality, produced by an active communities of developers
- The licenses were very liberal and allowed any use by the ALISS project
- There were no license costs for implementation of the ALISS Engine
- Flexibility - the software setup was changed as development progressed, with no costs in switching licenses (3 different database systems were used).



ALISS licensed all software using a liberal open source license. This meant that the ALISS software was available to anyone wishing to use it and/or extend it, while preventing anyone else from claiming exclusive rights to it. This also meant that the software was available to Scottish Government in perpetuity with no restrictions on its use or further development.

The use of open source in a government project was noted by Martin Belam, who was Lead User Experience and Information Architect at Guardian News & Media, writing about innovative ideas in the digital landscape:

**“ The ALISS project has not only used open source software, but gone one step further and made the code they are building open source. It is unusual for government sponsored projects to go down the open source route, both in using the software and in publishing the work that they have developed. Sharing the code gives another layer of value for the investment in the project. ”** <sup>52</sup>

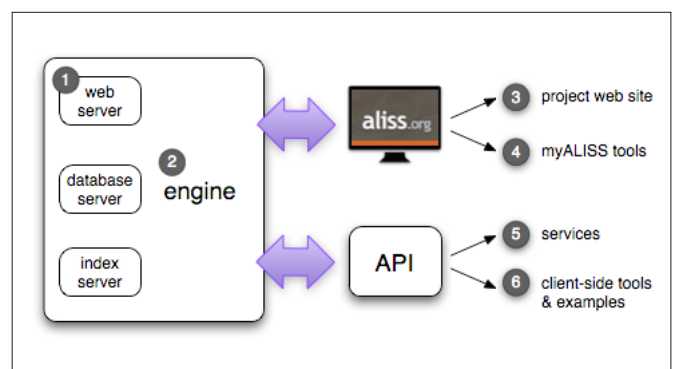
The approach to development was consistent with emerging government policy, as around the same time, 2010, the Scottish Executive Open Source Working Group published a paper on use of open source which referred to key elements:<sup>53</sup>

- The Scottish public sector should consider Free/Libre/Open Source Software (FLOSS) solutions alongside proprietary ones in ICT procurements and that open standards a prerequisite for all interoperability software development
- The Scottish public sector should seek to avoid lock-in to solutions that may prohibit the delivery of efficient public services

- The Scottish public sector should consider obtaining full rights to bespoke software code or customisations of COTS (commercial off-the-shelf) software it procures wherever this achieves best value for money
- Where software is produced in-house by the Scottish public sector, or through publicly funded research and development projects, consideration should be given to making this available as FLOSS.

The architecture was designed to be implemented in many ways, so that it could support separate but connected implementations. Such an approach was possible through the use of web (and related) standards. There would be six technical components to ALISS:

- The web server
- Engine
- Project website
- myALISS tools
- Services
- Client-side tools and examples.



## Specification

There were four aspects to functional specification of the Engine: data collection; data storage; data and access management; and data services for third party applications.

<sup>52</sup> Martin Belam, FUMSI – article no longer available

<sup>53</sup> Free/Libre/Open/Source Software: Scottish Policy Statement, A Report by the Open Source Software Working Group <http://www.gov.scot/resource/doc/1067/0049471.pdf> (web only)

## Data collection

The Engine collected data from a range of sources.

- Current aggregators - collaborating with collators of information, importing their data straight into the Engine would make their data more findable
- Smaller or less visible sources that might be missed by the main aggregators, making them more findable. These might be through individual submissions via a contribution portal or by adding a layer of semantics where this did not exist in the sources. ALISS would support source authors in improving the semantic mark-up of their content. The prototype demonstrated the benefits of adding location data and keywords derived by content analysis
- New services and future applications (an exciting feature of the data collection). The algorithm for the ALISS platform was generic, so could be applied to other areas of public services and beyond, for example local news gathering, sharing data. Publishing the Engine code as open source meant others could re-use the index-style platform for many other purposes (beyond health)
- ALISS as a set of services, providing infrastructure to make self management support more accessible to existing web services. In the longer term the Engine would provide an open resource for innovation. Once the infrastructure was in place there would be an opportunity for new applications to build on top to contribute to and draw from the Engine via its API. The range of possible client applications could not be predicted; a key ambition of the ALISS project was to encourage new uses and re-purposing the architecture
- Widgets (snippets of code) would be developed for a **“powered by ALISS”** search box that could easily be embedded in local and national provider’s web pages (i.e. from small organisations to NHS 24).

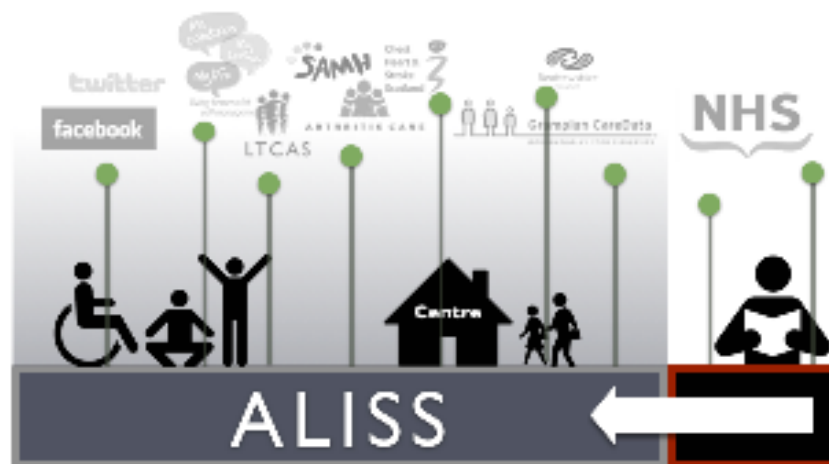
## Data storage

ALISS would index and not store resources, the working model was agnostic about the resources it indexed, at first it could be anything with a unique URL (Uniform Resource Locator, address of a web page) as only web-based resources were collected in the prototype. As a potential national information system, ALISS could provide standard URLs for existing web-based resources or for resources with no web presence (the innovation workshops generated ideas that would require indexing resources such as people, images, places, tweets, blog posts, experiences, etc). The working data model included a URL for the resource being collected along with simple metadata, which included a text summary describing the content, latitude, longitude and a WOEID (Where On Earth ID), which allowed a description of services which were area rather than point based.

The working model used an implementation of the MongoDB database, which is a scalable, high-performance, open source, document-oriented database. At the time of implementation (2010) MongoDB had just added geolocation features and this, along with the flexibility of the document-oriented approach, made it ideal for prototyping the Engine design in a way that could result in a usable system for piloting in the next phase. The Django open source, python-based, web framework was used to make a shell for managing the database and creating demonstrations of data collection and retrieval. Source code and some early documentation were published.<sup>54</sup>

ALISS was built to integrate with location-based support services (current at the time) such as Plings, Local People, Hophive, Chain Reaction and Enabledbydesign. Connections were made with these organisations to foster interoperability.

<sup>54</sup> <http://github.com/snowcloud/Engineclub>.



**ALISS won't store  
all this information,  
but will index it.**

## Data and access management

The functional specification required an account management system for individuals and/or organisations, with varying levels of trust over management of content. The content itself required flagging with topic-based keywords and moderation status. Existing directory services in Scotland used various standards and ad hoc lists of topic keywords.

Interesting observations from the innovation workshops, which influenced data and access management were:

- The added value of indexing layers which would add metadata and structures for describing and finding resources that were not in the originals (improving findability)
- Use of filters to manage content to ensure people / organisations could have their own "bespoke" collection of useful resources
- Community moderation and management of content, using networks with special interest and expertise to directly modify metadata to reflect their evaluation of a resource for their community.

## Data services

An Application Programming Interface (API) was prototyped for the Engine to allow retrieval of resources using keyword and location searches, or by ALISS resource URI. The ALISS Engine would be a part of a linked data ecosystem and with three roles:

1. Use resources with stable URIs from other national systems, for example activescotland.org.uk with its database of facilities and groups.
2. Provide a stable ALISS URI to resources that may be hard to find online, or are liable to have ephemeral URLs of their own.
3. Link resources in useful ways, for example linking a local exercise class with user experience of the class on an online forum.

## Making the Engine available

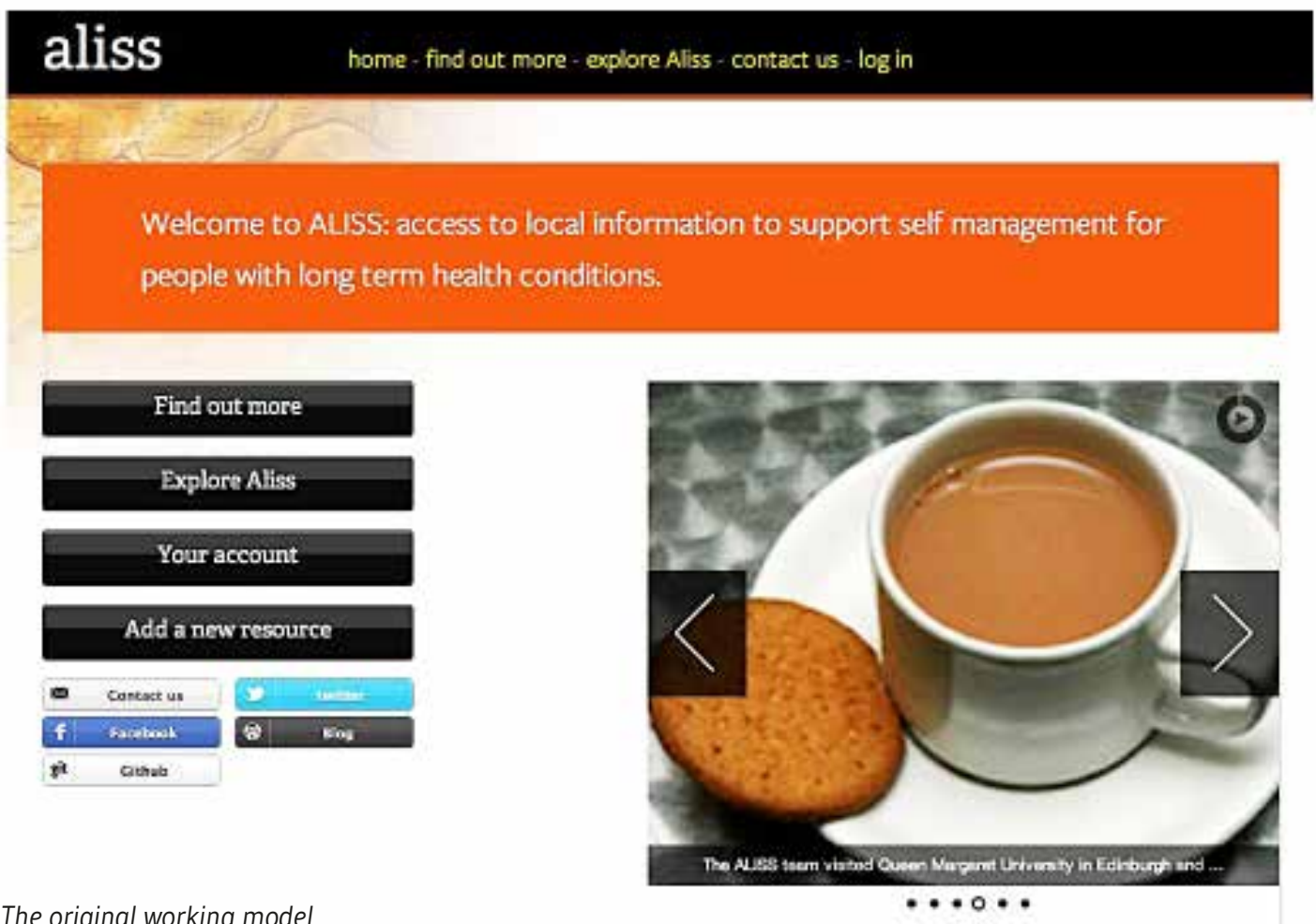
A prototype Engine was built in time for the innovation workshops in 2010, and presented to a group of local and national information providers in Scotland to discuss collaborative development and to identify the standards and processes needed to provide a national service. After the prototype had been shared in the OIP and with the Project Board, the Engine was made publically available.

## Linking technical development with the OIP

The team was learning from movements such as Social Innovation Camp who were introducing models to bring people with ideas together with those who have the technical skills to

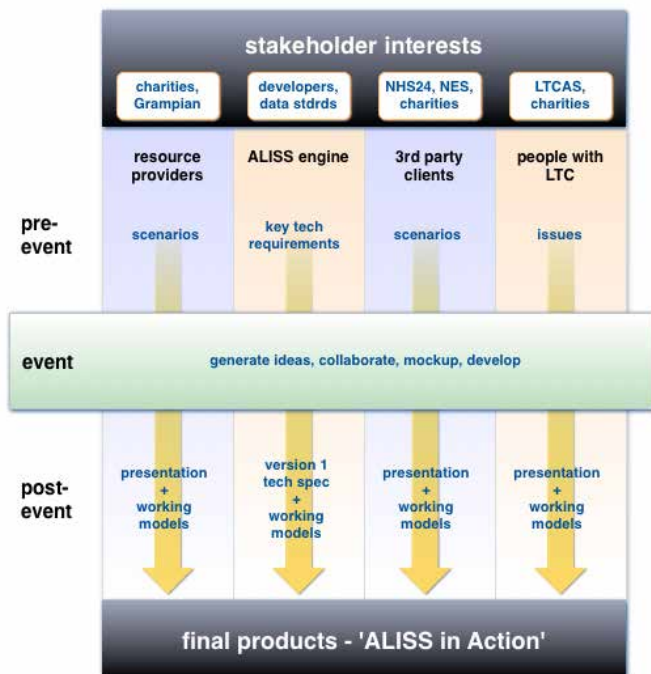
make them happen. The technical role included developing presentations such as videos and slides, feed ideas back into the community and use them to build the final products.

The key differences between ALISS and the usual social innovation models was that there would be less pressure to make working systems the products of the event itself, as expected outcomes need only be illustrative. For example, drawings or mocked up web pages that demonstrate what ALISS might look like - but with confirmation that the outcome is technically possible and socially useful.



*The original working model*

## How the innovation process would inform technical development:



The four main ALISS stakeholders were:

- Resource providers, including large public sector systems such as Grampian Care Data, charities with strong technical support, smaller organisations with no internal technical support
  - ALISS Engine, this would be the focus for technical development including the API<sup>55</sup>, indexing, content management, storage and distribution
  - 3rd party client systems, for example NHS 24, NHS Education Scotland, social networking projects and other systems that would use ALISS and contribute resources
  - People living with long term conditions to ensure that ALISS benefited those for whom it was intended.
- A group in the long term conditions stream brainstorm an issue: **“When I see things on locally, I need to know if I can do it on a Thursday, the only time my caring responsibilities allow, and if I can I get a bus?”**. The group comes up with an idea for presenting resources on a grid to show the times resource is available, with a visual indicator of their proximity to the user, and travel links. At the workshop, they meet Provider and ALISS Engine streams to see if there would be resource data to support this. At the end of the event, they demonstrate mock-ups of how this would be accessed and what it might look like.
  - A group in the 3rd Party Client stream works on how ALISS might be linked to NHS 24 content providing quality assured information to the public.
  - A group forms round a proposed schools project. This group cuts across streams, with educational input about integrating asset mapping and ALISS into the school curriculum, technical input on data capture and integrating a school’s ALISS resources with the school’s web site.
  - A group forms around - **“I’m lonely, how can ALISS know a local exercise class might help when that’s not what I asked for?”** The problem is that a resource provider can only ‘tag’ their resource with what they think people might ask about. Other connections might be useful but cannot be predicted without creating a huge burden on data input. Technical input to the group identifies that the ALISS Engine could support a secondary index which can connect tags, such as ‘loneliness’ and ‘exercise’. The group prototypes how this might work.

<sup>55</sup> API: an Application Programming Interface. This specifies how systems can electronically connect with the ALISS Engine and exchange data.

## Curation

Just as librarians and art galleries curate a collection, it was thought the same approach could be used to curate a collection of resources in ALISS. This would represent a way for users to collect, organise and maintain their own collection of useful resources. This approach fitted well with the ethos of self management and would spread the workload. Curation would provide a method to:

- Improve findability of resources by enabling users to add curations (tags)
- Create a personal collection
- Apply filters to exclude resources which were not useful
- Develop a self-regulation approach to moderation and quality assurance
- Develop a function to report a resource to block unsuitable material.

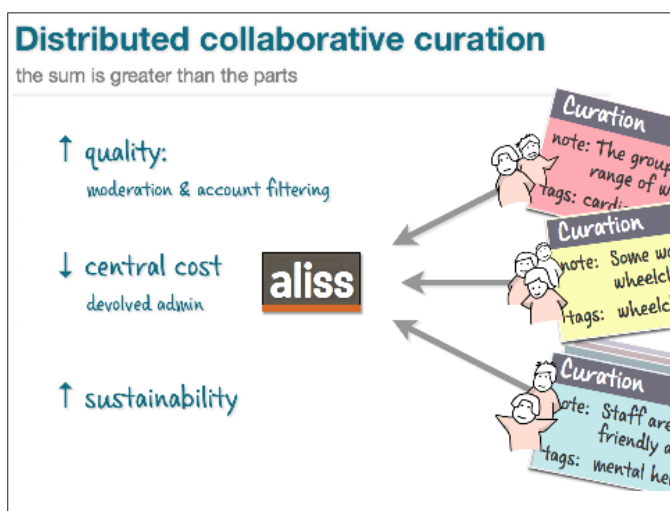


Figure 5 Distributive collaborative in ALISS

The Engine would require to support moderation and resource flagging across distributed networks, additional and curated metadata and reputation levels. It was clear that 'reputation management' was relevant and would become more important once ALISS was scaled up across the nation.

This thinking was crystallised during workshop discussions in November 2009, when community organisations suggested 'user panels' could be formed to moderate content, an idea which was echoed during the OIP in 2010. A participant, Joanna Ptolomey, had an understanding of community moderation and content creation, and was a member of a key intermediary community, the Scottish Health Information Network (SHINE). SHINE focused on NHS services, higher education, voluntary sector and commercial agencies and staff included librarians, information scientists and health professionals. Joanna was interested in the ALISS vision and agreed to collaborate on the following:

- Broker contact with the Scottish Health Information Network (SHINE)<sup>56</sup> to spark their interest in ALISS
- Address the potential problem of different classification systems used in directories of resources
- Collaborate with ALISS technical developers to create a version of moderation support in the Engine
- Contribute to a model for curation, moderation and classification of content, learning from other domains (case studies)
- Contribute to the February 2011 curation workshop.

SHINE members suggested content required "shepherding" or "chaperoning" and that technology could offer a level of automation, but people and communities were key to making content useful and valuable. Joanna gathered case studies to provide examples of how others organised their information:

### BBC Scotland<sup>57</sup>

The BBC had about four million physical items, equivalent to one million hours of material, and so tagging and classifying content was key in such an enormous archive. How this was done provided insights into how stewarding and chaperoning resources worked at a large scale.

<sup>56</sup> Shinelib.org. SHINE: Scottish Health Information Network. [Online]. [Date accessed 03/06/15]. Available from: URL: <http://www.shinelib.org.uk/>

<sup>57</sup> The BBC television archive. [Online]. [Date accessed 01/06/15]. Available from: URL: [http://www.bbc.co.uk/archive/tv\\_archive.shtml?chapter=1](http://www.bbc.co.uk/archive/tv_archive.shtml?chapter=1)

## The Guardian

The Guardian had no formal hierarchy or classification, it was very organic with no rule about the maximum number of tags per resource as they were chaperoned by stewards (in this case sub-editors) who ensured every piece of content had a tag and based the root of their taxonomy (tags) process in a system that existed – the old news desk. Content could not be deposited into the system without a tag and widgets were used to autosuggest tags, an idea which was subsequently used in ALISS. Within each news section, stewards monitored the flow and creation of tags which served as an alert to potential different use of content. This was useful learning on how tags could be managed (spelling, duplication, etc) in ALISS.

## NHS Greater Glasgow and Clyde Patient Information Service

The NHSGGC Patient Information Service content was mainly condition-specific and was derived from assured organisations, such as the NHS GG&C Public Education Resource Library and NHS24 (Inform). Those at the service were aware of the considerable overlap with holdings of other organisations. It was also noted that brief interventions, for example for smoking and alcohol, relied on a level of spontaneity and context-appropriate tailoring that could be difficult for an institutional information service to support. Patient information workers operated as stewards, spotting different ways to pull information together, and creating organisational partnerships.

## Sharing Strength (closed 2011)

Coleen Young, of Sharing Strength, a Canadian Breast Cancer online resource, explored the role of human “stewarding and chaperoning” information. It was noted that the role:

- Was key to the success of the community
- Allowed the community to expand without reinventing the wheel
- Stewards allowed a community to shape their own information needs

- Was important in creating partnerships with people, groups and topic areas
- Provided a focus for a community (or group) to curate and moderate information and create communities within a bigger group (for example, Sharing Strength was a large community with a number of smaller specialised groups).

## Motor Neurone Disease Scotland (MND)

MND did not have its own classification system, and used the SHELCAAT system.<sup>58</sup> This example encouraged the idea that the ALISS Engine could present a more flexible way for organisations, such as MND, to ‘set free’ its information.

## Glasgow Women’s Library

The library had developed a classification system, however, the idea of an open sourced version for library content was not considered possible. This re-enforced appreciation of the need to devise a system that allowed labels to be layered on to resources without disturbing labels that had already been applied. The Women’s Library stewarded their information manually and considered this a vital step in sharing and curating information in ways that users would find useful.

## Citizens Advice Scotland

Citizens Advice Scotland (CAS) provided an insight into how an organisation responded to different issues and external stakeholders. CAS headquarters developed national community and legislative content, which anticipated users’ needs by monitoring national policies and statute or regulation. Local bureaus were more flexible and were not restricted to using the central Advisernet system, linking with local resources to curate a different type of content, which was less ‘quality-assured’, but appropriate to local circumstances. This presented an example of how relationships between local and national curators or ‘account holders’ could relate to each other and be supported in the ALISS Engine.

<sup>58</sup> Scottish Health Libraries Catalogue, [Online] [Date accessed: 01.12.14], Available from: URL: <http://nhs.hosted.exlibrisgroup.com/F?RN=406947645>

## Curation as an approach to quality assurance

The case studies on curation provided a useful perspective for the technical team as they considered moderation and tagging in the next version of the Engine. This was a significant step in developing a robust approach to the issue of quality assurance, which was a concern for institutional stakeholders in particular. The work also highlighted the importance of work with human communities and networks, as it was clear that technology and automation could only partially support the process.

The moderation process was rehearsed in more detail at the February 2011 workshop, when people confirmed that although they did not consider themselves 'moderators of content' there were commonalities in the approach people used in assessing the quality and/or usefulness of content. Insights included:

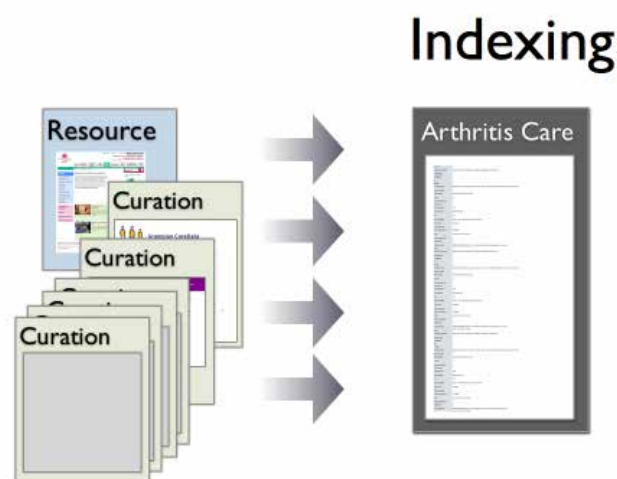
- There were two types of content; 'NHS quality assured' (generally condition-specific) and community assured (often hyperlocal - a term which used in relation to local online news or content services)
- Content sourced from a reputable organisation will indicate the credibility of the resource. Ideas to address reputation included developing a way to create (curate) a personal collection by applying filters, and a 'follow' function which alert users when new resources were added by a trusted account
- People felt most comfortable with content they had an affinity with, for example, a specific condition group, or resources associated with a geographical area
- Information professionals and librarians have particular expertise in moderating content, topic areas and types of evidence
- Source organisations, networks, and communities used different processes but shared general themes
- The value of existing communities (for example, LTCAS had ready-made communities and Sharing Strength

harnessed the power of Canadian cancer groups). The Guardian did not dismantle their old news-desk arrangement as they knew that established communities would be at the root of managing the digital world

- The role of the steward was important in harnessing the power of the community. Most case studies used this type of role: the Guardian tag managers (sub editors), the BBC production managers, the NHS Greater Glasgow and Clyde Patient Information Service manager and the Sharing Strength community manager.

## Classification systems:

Organisations used different methods and varying degrees of complexity to classify content, no one universal classification system would fit everyone's needs. The case studies showed that taxonomies or tags offered benefits in managing and finding content, less administration and a more flexible approach for individual content. This suggested the concept of a resource with attached tags which could be layered, so different curators could add to the richness of the data without obscuring earlier contributions, and improve the findability of the resource.



*Index function of ALISS - adding tags makes resources more findable*



# Quality Assurance



One of the most challenging aspects of developing a national system to share citizen's knowledge of support was quality assurance. This was a particular concern in traditional healthcare information environments, where quality assurance was paramount. However, the team was being reassured by people living with long term conditions and others, that they needed both quality assured and informal support, the latter was often local and personal and not likely to be kite marked. For instance people living with mental health conditions, described the benefit they feel from digging in allotments, or meeting people to have a walk with - not activities that can be quality assured and, as someone remarked, not likely to be as dangerous as a side effect of a medicine.

Having a role in passing on information about informal support, such as local walking groups, fitted the ethos of self management, but was uncharted territory for health and social care staff who were used to referring to sources, which were quality assured. There was no intention that ALISS should be an information "free for all" which would be liable to inappropriate use, the issue of quality assurance was addressed by creating methods to:

- Curate a personal collection
- Apply filters to build your own collection of useful resources
- Apply a self-regulation approach to moderation
- Improve findability of resources by enabling users to add curations (tags)
- Report a resource to block unsuitable material.

Although ALISS could not have a role in distinguishing degrees of quality, a technical approach was required to allow safe management of indexed information. It was resolved that:

- ALISS would begin by only accepting new content and curations from account holders, accounts would be withdrawn if any abuse of the system
- The Engine would support moderation of content, so people could 'report as unsuitable' anything they find in ALISS
- Those who want more control, such as NHS 24 and NHS Boards, would be able to curate their own content and only use their own collection, or filter their searches to view only the accounts that they trusted

## Relevance of Information

A system of applying filters was developed to ensure relevance of information, for instance, organisations requesting information on specific topics by location (‘show me exercise classes in Arbroath’) or users who only wanted access to their own collection of resources or to only quality assured information. It was predicted that health practitioners interested in social prescribing would require more stringent filters and so the Engine was designed to cater for both perspectives, so that users could view both trusted and untrusted resources, without hard-

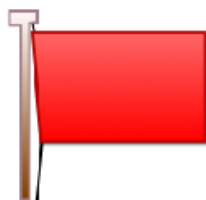
wiring one or other into its design. Adding tags would not only make resources more findable, but filtered ALISS searches would just return their own curated content, or accounts they wanted to subscribe to.

One idea was to develop reputation levels with a higher status for more trusted users, for instance established information providers (e.g. NHS Boards and NHS Inform). Users wishing to access information which is quality assured, for instance, by NHS 24 / NHS Inform, could do so by adding an extra “QA” tag, queries to the Engine will search only those with “QA” tag searches.



## moderation reputation levels

- higher status for more trusted users
- information providers would be high level
- others would earn reputation over time...
- ... by positive behaviour, eg good content



## moderation resource flagging

- e.g. *unknown, published, issue raised, serious issue raised, blocked*
- multiple flags from different users
- consider source of flag – user reputation
- ‘OK for NHS’ ?

## Filtering resources to improve relevance

Individuals, groups and organisations, such as a general practice, could use filters. By applying a filter, a practice could choose to access only their own collection, or resources collected by neighbouring practices, or extend wider to include other community resources.

### Practice search

just our own resources



an example - client side tools can search ALISS however they like

ALISS search on GP practice directory only

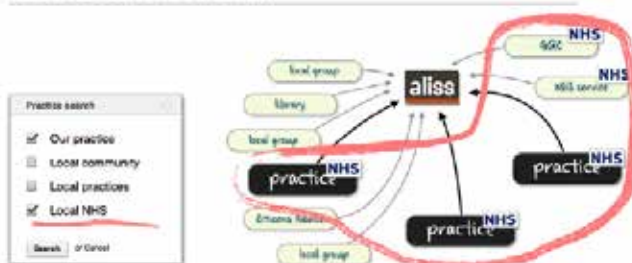
### Practice search



ALISS search on all local GP practice's directories

### Practice search

search accounts with NHS flag



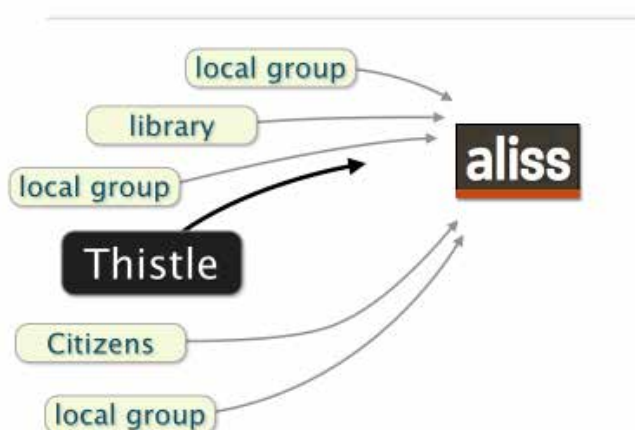
ALISS search extended to all local practices and trusted NHS directories

## Related ALISS software development

### Account Management system

In addition to developing software for the ALISS Engine, an account management system was created to ensure that users could only add content if they had account and opening an account on ALISS allocated a unique identifier for quality control. Distributing the effort of gathering information about local support could be shared between account holders, such as Citizens Advice Scotland, local groups and Thistle Foundation.

### Using ALISS accounts



*ALISS accounts contributing to local information*

Software was also developed to allow two-way contact with account holders to report a resource if there was any concerns, for example, if a user noted information which was out of date, inaccurate or inappropriate they would click the "Report" button". This would trigger a message to the ALISS administrator who would block (but not withdraw) the resource until the resource was checked. This worked well as it was a very quick process for users and encouraged the community moderation aspect of ALISS.

## ALISS IT

Another useful function was adding resources directly from a webpage to a user's ALISS account. An ALISS bookmark was developed based on the team's experience of spotting useful things while browsing the web and using bookmarking sites. It was a simple idea - by adding a bookmarklet (which was named ALISS IT) from aliss.org to the browser toolbar, a user could add a resource by highlighting text on the resource web page and click on ALISS IT. When logged into ALISS, a pop-up appeared containing the resource addition form with the URL and name of resource already populated. By adding a few details and clicking submit, the user would add the resource to their account without navigating away from the website. This added the new dimension of quickly collecting data 'in the wild' and encouraged participation by removing the need to copy and paste information from webpages into ALISS. This works well if users have up to date browsers, but unfortunately many NHS Health boards do not use latest versions.

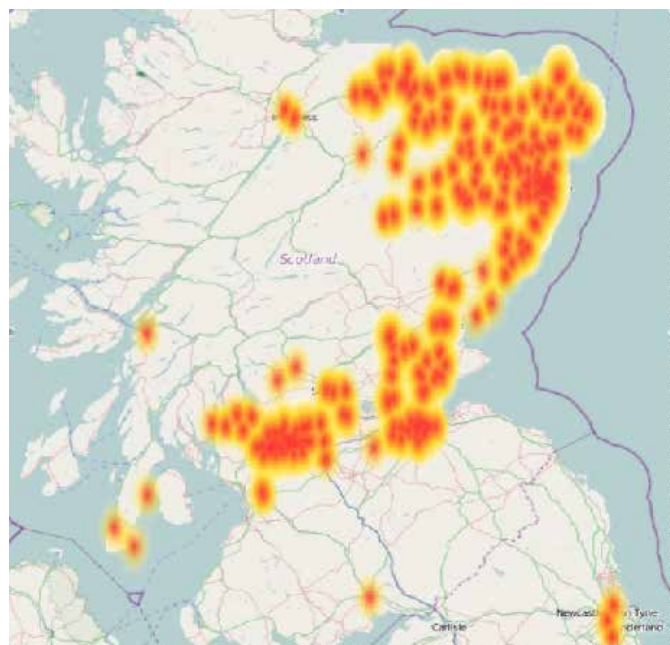
## ALISS Heatmaps

Using ALISS analytics, heatmaps were generated which represented a useful map of self management resources. It was predicted that heatmaps would be a useful tool for health and social care teams to gather intelligence for future planning, monitor local support and spot gaps in self management provision. An example of how resources could be aggregated in Greater Glasgow and Clyde is shown below:

### GGC aggregations



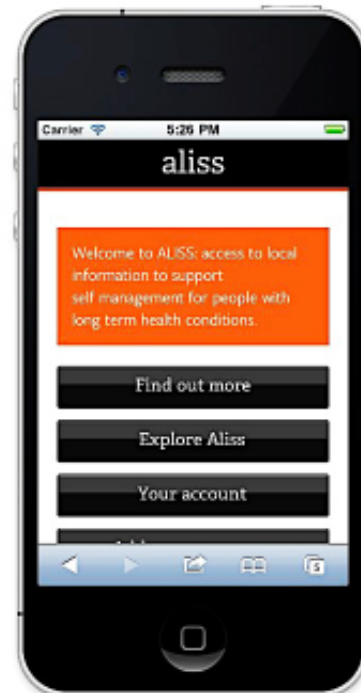
- could create feed from accounts tagged GGC
- practices, GGC services, libraries, LA, CAB, 3rd sector groups
- LTCAS over 200 members



*A self management map of Scotland using data collected in ALISS*

## ALISS and mobile technology

ALISS was designed for use with mobile / smart phones, so that people "on the move" would have easy and quick access to information on local resources. This was developed after feedback from GPs and others who said they would need to access information while on house visits and away from computers.



# Reflecting on development of ALISS

Development of ALISS coincided with an improved understanding worldwide about the rise of lifestyle diseases, the effects of inequalities in health, living with multiple conditions and the nature of complexity. There was a call for new systems as existing frameworks were ill-equipped to cope with this more networked, complex landscape.

Developing ALISS was more than creating a local information system, it was a passage through the realities of negotiating formal and informal infrastructures while trying to build a networked, coherent system. The key enablers were personal relationships and local and national networks.

The team linked what people suggested might help loneliness, the challenge of finding support and the daily lives of people living and working in deprived areas. Throughout early development, the team witnessed the potential for ALISS to be a practical tool to mobilise support, which would link people working in local authorities, social workers, school teachers, housing, police, librarians, adult literacy tutors, third sector organisations and youth groups. Once people had an opportunity to consider the value of community support there was enthusiasm for collaboration and mutual signposting, however, a reluctance to adopt change, understanding of how to collaborate, formal structures and busy workloads often make these connections hard to create and sustain.

The potential for connections to be made between preventing poor health, levels of literacy, self management of long term conditions, schools and communities was clear to all involved and was one of the most interesting aspects of ALISS. The early work with

the adult literacy group was important in gaining a consensus for what ALISS should be – a tool to find, understand and use information about support to self manage. The collaboration with Trinity Academy was significant; the concept of young people contributing to improving community health was immediately understood by teachers and pupils and was embraced in a “non-health” environment. Embedding ALISS as a tool for integration in local communities is an exciting prospect.

A key learning point was that linking data also means linking people and resources, the data indexed in the Engine has potential to be an extremely useful source of local and national intelligence.

The team was grateful to have an opportunity to be involved in a project which aimed to contribute something for the common good, and do this with an eye on protecting the public purse. ALISS will continue to be developed and will no doubt be adapted to suit local and national priorities, the flexible nature of ALISS should ensure that it becomes a local information system for Scotland and beyond.

# Acknowledgements

The ALISS project team is very grateful to the people living with long term conditions who attended our workshops and were generous with their ideas, thoughts and experiences. We are also grateful to Scottish Government for funding an innovative venture, with special thanks to Dr Derek Feeley CB, former Chief Executive of NHSScotland, for recognising the potential for ALISS to be a world class information system.

*We wish to acknowledge our appreciation to the following contributors:*

## ALISS Health Literacy

Adult learners in Edinburgh's City Literacy and Numeracy project, Elspeth Hosie, Jo Aitkenhead, Health Literacy Community Learning and Development workers and Kate Burton, Public Health Practitioner.

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## The ALISS team 2009-2013

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## The ALISS Project Board 2009 – 2011

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## Derek Hoy (1954 – 2012)

Developed the software and plan for ALISS. Illustrations used in this report are copies of Derek's presentations.

# Links to information about ALISS:

Three screencasts which explain how ALISS works:

Screencast 1.

Introduction to ALISS:

<http://vimeo.com/23257731>

Screencast 2.

The ALISS Engine - explaining the ALISS technology:

<http://vimeo.com/22614113>

Screencast 3.

Explaining th ALISS Engine

<http://vimeo.com/11986849>

ALISS Engine open source code on GitHub:

<https://github.com/snowcloud/engineclub/>

ALISS website for FAQs and activities:

<http://aliss.org/>

The Open Innovation Process:

text, presentations, videos, photographs of innovation process with materials for re use.

<http://alissproject.wordpress.com/>

The Boys' Brigade "Yes I Can" Long Term Ambitions, Resource Materials on the Self Management of Long Term Conditions For Young People.

[http://www.alliance-scotland.org.uk/download/library/lib\\_565edcd0a0769/](http://www.alliance-scotland.org.uk/download/library/lib_565edcd0a0769/)

The ALISS Health Literacy Report

[http://www.alliance-scotland.org.uk/download/library/lib\\_5461d6ec4ca33/](http://www.alliance-scotland.org.uk/download/library/lib_5461d6ec4ca33/)

Asset Mapping with ALISS - in Kirkintilloch

<http://www.slideshare.net/pashe/aliss-and-local-health-assetmapping-a-cartoon>



# References and further reading

Health and Social Care Alliance Scotland  
<http://www.alliance-scotland.org.uk/>

GPs at the Deep End Reports  
<http://www.gla.ac.uk/researchinstitutes/healthwellbeing/research/generalpractice/deepend/reports/>

The Links Report: Developing the Connections between General Practices and their communities  
<http://www.scotland.gov.uk/LinksReport>

Improving Links in Primary Care blog  
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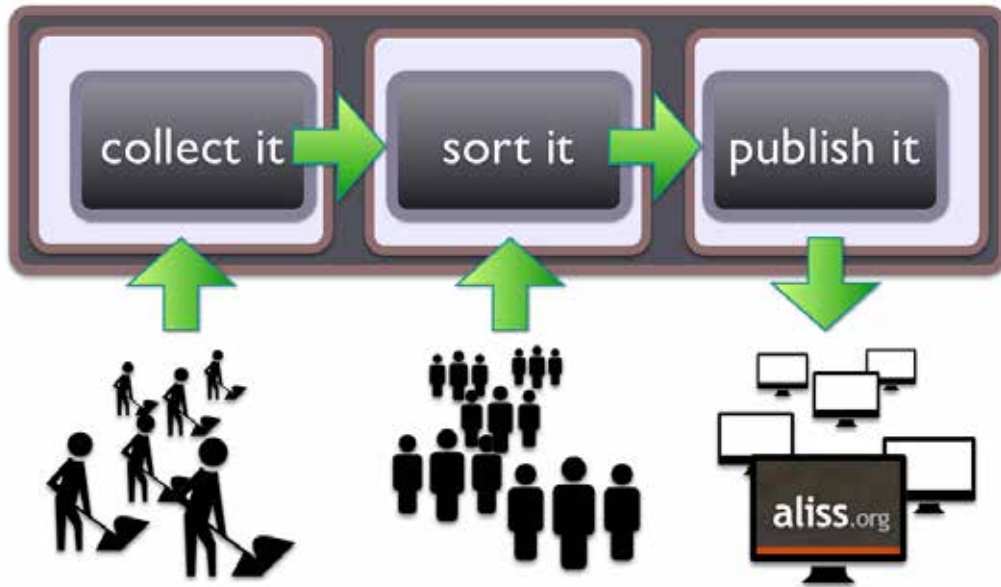
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