

Liberating the NHS: An Information Revolution¹ – Making it happen Response from ADASS & LGA

Background

The **Association of Directors of Adult Social Services** (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of social care, ADASS members often also share a number of responsibilities for the commissioning and provision of housing, leisure, library, culture, arts and community services within their Councils.

ADASS members are jointly responsible through the activities of their departments for the well-being, protection and care of their local communities and for the promotion of that well-being and protection through the use of direct services as well as the co-ordination of and liaison with the NHS, voluntary agencies, private companies and other public authorities.

ADASS members have leadership responsibilities in Local Authorities to promote local access to services and to drive partnership working to deliver better outcomes for local populations. They participate in the planning of the full range of council services and influence Health Service planning through formal and informal partnership arrangements.

Local Government Association (LGA) – is the voice of the local government sector. We work with and on behalf of our membership to deliver our shared vision of an independent and confident local government sector, where local priorities drive public service improvement and every councillor acts as a champion for the people they represent. The 422 authorities that make up the LGA cover every part of England and Wales. Together they represent over 50 million people. They include county councils, metropolitan district councils, English unitary authorities, London boroughs, shire district councils and Welsh unitary authorities, along with fire authorities, police authorities, national park authorities and passenger transport authorities.

ADASS and the Local Government Association welcomes the opportunity to contribute to the Department of Health Consultation on the Information Revolution.

This paper that underpins our response has been produced with reference to the DH overarching strategy paper, 'A vision for adult social care: capable communities and active citizens'², the current DH consultation 'Transparency in Outcomes: a framework for adult social care'³ and the recent Adult Social Care sector-wide commitment "Think Local, Act Personal"

ADASS and the LG Group has identified four critical messages arising from the consultation

1. Strong alignment with the **Vision of Adult Social Care**, with the emphasis upon personalisation and self-care

1

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_120598.pdf

2

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_121667.pdf

3

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_121660.pdf

2. Fundamental shift to the **citizen being placed at the centre** of this information revolution. This will require new consortia and resources to be developed and will need to address the fact that the proposed business model does not necessarily adhere to current Local Authority boundaries. Information should be just as easily accessible to self-funders and members of the public as to Local Authority supported service users

3. **Governance** and need for further clarity in the details to fully realize the strategic ambitions of the proposals

4. Need to align proposed **strategy with details** / deliverables

In general terms, it is noted that 'simple is cheap: complex is expensive and difficult to understand, particularly for self-carers and developers.'⁴

1A. Adult Vision: Continuity of overall policy agenda is clearly welcomed with the opportunity to capitalize on much of the current work to date i.e. the Information Centre supported SIIP, review of indicators, CAF etc.

It is noted, that the proposals would seem to be based upon the health model, with social care 'added on'⁵. This does pose some issues, for example the self-care agenda is more developed in social care as the Parallel Universe papers suggest.⁶ Proportionately, more social care is commissioned and funded privately and not always from CQC regulated organisations. This has a major bearing. It is also important to have open access to key details on costs of services and addition information about private providers, including health, as this forms a significant proportion of the market.

ADASS working with CQC in this area would seem a useful way forward, although the problem of unregulated social care does remain (e.g. personal assistants, housework etc).

2A. Citizen at the Centre: As the Internet is without boundaries, the model of each Local Authority buying a system and installing it for 'their own' citizens no longer makes sense, and could involve re-procuring essentially similar systems multiple times. The Shop4Support, QuickHeart etc, are all models already in use, commissioned by individual Local Authorities and in this respect do not easily handle cross-boundary access. This leads to the need to develop a more suitable business model to support a fully personalised agenda across organisational boundaries.

This paper suggests some options in this respect with references to Mumsnet. This is a cross-Local Authority development and also offers, through advertising, an alternative funding source. The key point is not to try and develop Local Authority based systems for the public, but to start from public based system, irrespective of Local Authority / organisational boundaries. The focus has to be on providing the public with tools to help them buy social care easily, appropriately, knowingly and efficiently, whether or not they are supported by Local Authority funding.

There are two main areas that need to be covered in any new approach:

- A. Systems or portals to support the citizen in handling their own information. For example, the Mumsnet model seems a useful example of what this might look like. The Terence Higgins Trust will launch a support system early in 2011 for people with HIV/AIDS
- B. Systems to provide and foster the market place where citizens can safely research, buy and provide feedback on services they use. These are already in development at a Local Authority level in Shop4Support, QuickHeart etc.

One key point is that in establishing cross-authority/ organisational systems, possibly sponsored in conjunction with major voluntary organisations, could be seen as effectively

⁴ The problems with the 'whole systems demonstrators' provide a salutary lesson in this respect.

⁵ The role of the health based Information Centre in business analysis may need to be reviewed.

⁶ by Bob Hudson and Melanie Henwood

creating e-social care services. Given the need for public assurance (these e-social care services may need CQC oversight), the following key elements would need to be covered:

- Do the systems continue to meet citizen needs? With a number of competing systems the market may assist in this, but should either a monopoly or significant market dominance emerge, some control would be required.
- Are there reasonable security and confidentiality controls in place? For example, there would be a need to undertake appropriate vetting of staff who have access to market information about vulnerable dependent citizens

Maintaining and developing these market systems in line with continuing developments and customer feedback requires a credible and reasonably secure funding stream. It would appear the resource options are:

- ADASS and Local Authority joint enterprise model or promotion of consortia
- Central government funded
- Advertising funded, (i.e. Mumsnet)
- percentage-take on transactions, as with Shop4Support

- Or combinations of these options.

It is worth noting that some major players are in this market already, with GoogleHealth and MicrosoftHealth each offering a possible portal, albeit based on health rather than social care.

On a simpler level the critical point is whether any portal is actually required. Most IT-literate users can tie together their own elements into a personalised portal. This could be as simple as Internet Explorer favorites or more sophisticated in Facebook etc via apps that may be encouraged to develop. While something like Microsoft sky-drive or Dropbox could be used to store documents (whatever their source) and make them available according to the citizen's wishes.

Whichever model is developed the key function is to bring together a range of elements including:

- Banking details for financial management, including online banking services
- A direct payment account if in place⁷
- Local Authority details, where assessments or care plans are agreed with the LA, including a self-assessment tool.
- Private care assessment services, where assessments or care plans are developed with a private provider, or relatives/friends.
- Personal care plans as shared with carers
- Specialist sources of information, such as Age UK, Mencap et al
- Health information.

Templates for portals using generic browsers could cheaply and easily be developed and shared. In effect the outcome is the provision of both records for the citizen and for the organisation, but managed and held separately but with flows of records probably by secure email between the citizen and the Local Authority.⁸

3A. Governance: The practical realisation of all of the proposed developments is a real challenge. The options outlined above look at the system implications, but this leaves the critical standards and governance issues that would need to apply to all the offerings.

ADASS and the LG Group both have a potential role in working with system providers (Open Objects, QuickHeart, Shop4Support etc) to identify consortia or alternative funding streams to develop these market places. There should be no need for 152 separate systems, each being purchased and maintained locally, particularly when major economies of scale could be

⁷ The LA interface for this is provided by the BACS services already in place. A debate could be had as to whether the benefits services would be best placed to deliver this service.

⁸ A more radical option could be for the LA assessor/care manager to use the citizen's record system and share/copy content to make the formal record, e.g. a care plan is jointly sketched on paper, and then a copy made for the LA and added to the case file to act as the formal organisation record. Generic tools such as DropBox could be used to share information.

realised, along with the opportunity to create information systems across all Local Authorities for the benefit of all citizens.

The requirement for standards is critical, and ADASS, the LG Group, CQC and the NHS Standards Board all have a role to play in developing these. Developing standards in a rapidly changing area is immensely difficult because they can potentially constrain development, and cause over-development if evolved in isolation from practice. However it may be useful to focus on the key statutory responsibilities:

- Information provision about local services, including the contentious issue of pricing (provided by suppliers and overseen by Local Authorities). and availability of services.
- Information about Local Authority support, including self-care assessment, RAS calculations⁹ and Direct Payments arrangements.
- External quality assessment of service (provided by CQC, available as a web service) as well as Local Authority qualitative feedback (e.g. which services the Local Authority uses)
- Customer comments on services, such as 'I want great care' for doctors¹⁰
- Production of quantitative anonymised data from the systems to assist commissioning and service development. Services commissioned outside the market systems will be missed, but could be estimated through sampling.

Standards for data developed in these areas enable the suppliers of systems to handle the customer journey in different ways. This potentially maintains a degree of constructive competition and a dynamic in developing the systems for citizens as the users.

4A. Synergy between the strategy and the detail. Although these proposals do not delve into the all the detailed informatics considerations, it is critical that the complexities of health and social care information are handled and are deliverable technically. Therefore the strategy, the business model and informatics all need to stay in step. The type of critical issues that would need to be addressed includes:

- Technical standards for sharing organisational information with users i.e. – this could be as simple as pdf format which the users might download and file in their own storage.
- Details of basic standards and sanctions for non-compliance
- Clarity as to what information should be made available, e.g. care plans and assessments are most likely to be shared, but should all records, such as those of telephone conversations, be included?¹¹
- Possibility for users to create their own assessments/care plans from models/tools available on-line, and then share these with the local authority
- At what point should the access to a self-care record be taken over in cases of abuse. In effect at present this is only when the Court of Protection is involved or at the request of the service user.
- To what extent must private companies provide information on services, their costs and feedback?
- Coded data is needed to create information that can be analysed, but with increased self-recording how are the data standards to be maintained? The terms data and information are used loosely, but have significant technical differences, especially when all parts of society are being catered for.¹² (Coding might happen as a semi-professional exercise following the sharing of material from the user)
- The costs of extra data collection by professionals¹³ pose a major resource issue. The Munro report, partly in response to the children's ICS recording requirements, is addressing some of these issues. This links in with a later question of balancing the costs and benefits of data driven information, and the review of indicators.¹⁴
- The CIPFA guidance on accounting for Direct Payments has a significant effect on both the relationship with the recipient and the systems needed.¹⁵

⁹ There is an interesting debate as to whether the data and rule driven RAS models could or should be nationally provided by an organisation such as Age UK. Each LA's rules are available under FOI so with self-assessment indicative resource allocations could be calculated.

¹⁰ <http://www.iwantgreatcare.org/>

¹¹ the suggestions at para 1.8 are mainly focussed on generic public information.

¹² para 1.6, p11, also comments on quality at 2.13

¹³ consultation question 26

¹⁴ consultation question 30

¹⁵ purchased via CIPFA

- Efficiencies through voice (and video?) recording are noted, but this is data that cannot be easily analysed into information.
- Access to information is seen as internet based, with mediated access through CAB et al. Paper channels may also be required.
- The wealth of health and social care information that a citizen might have access to could be great. It is likely that the citizen would want to share their personal information with key people (carers, partners, family doctors, providers et al), but it unlikely that all would be shared with all these. The issue of sharing information with carers or with households also needs consideration. Controlled sharing therefore, although complex seems critical. It may be that the ability to share via email, or on a web service designed for such sharing, is the initial deliverable as some of the work in multi-agency information sharing has already shown.¹⁶

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¹⁶ the Merlin system between LAs and the Met Police in London and work with care plan sharing. Also Microsoft Skydrive or Dropbox or similar web tools can play a role here.

Consultation questions – Chapter 1

This response is written solely from the perspective of social care,

It could be argued that the future of social care in information terms is different from health. Professionals in health will always need systems to implement and feedback on the success of their increasingly scientifically based solutions to identified disease (Medical Model).

In social care, a more holistic Social Model is applied in which the citizen's choices and outcomes are paramount and it is the role of social care to support and assist the citizen in meeting these. If truly enacted in systems this would cede control of information to the citizen, except where largely private service providers recorded their actions. The assessment of needs and the plans for action become the responsibility of the citizen, supported where necessary by professionals or advocates/carers.

This radical step is likely to result in less data collection, and less data focus, so that the judgements of what work become less pseudo-scientific and more personal, more like hotel comments on a hotel booking web site. Research methods become more appropriate, which can handle the fundamental challenge of outcomes being more personal and subjective than standard,

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

In social care there is professional commitment to the joint nature of ownership of information. This is key in ensuring the citizen is in the driving seat and that information systems are easily understood and accessible E-mail, social networking, understandable guidance and marketplaces seem to be what works well for citizens at present. Extending the ability to receive and send e-mails securely (building on NHSmail and GCSX) would be a good start for both citizens and care agencies (private or 3rd sector), enabling government bodies to share sensitive information with them quickly and receive material about their needs and care. This builds on technology already available, making it cost effective.

Q2: What do you think are the most important uses of information, and who are the most important users of it?

The most neglected users of information at present are self-funders and self-carers. The information revolution is an opportunity to place the 'data subjects' at the center.

Speeding up communication and service can also be vital at critical moments, where different agencies need to work together

Q3: Does the description of the information revolution capture all the important elements of the information system?

In social care the key elements omitted are:

- 1 The need to develop an informed and secure market place for social care services and subsequent contracts.
- 2 The key links required for paying for services.
- 3 Greater focus on secure communications between citizens, service providers and local authorities.

Q4: Given the current financial climate, how can the ambitions set out in this consultation - to make better use of information and technology to help drive better care and better outcomes - be delivered in the most effective and efficient way?

A three-pronged approach is proposed:

- 1 The sponsored development of a limited number of competitive national market place services, which all meet minimum standards.
- 2 A range of funding options:

- o ADASS and Local Authorities to take forward a joint enterprise model or promote consortia
 - o Central government promotes
 - o Advertising funded, tapping into the big market out there (i.e. Mumsnet)
 - o percentage-take on transactions, as with Shop4Support.
- a. Or combinations of these options.

3 Helping citizens create and share their own information repositories

Q5: Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?

The requirement for standards is critical, and this would appear to be where ADASS, the LG Group, CQC and the NHS standards board have a role to play. Developing standards in a rapidly changing area of activity is immensely difficult because they can potentially constrain development, and cause over-development if evolved in isolation from practice. However it may be useful to focus on the key statutory responsibilities and identifying minimum standards in these areas:

- a. Information provision about local services, including pricing (supervised by LAs) and availability of services.
- b. Information about local authority support, including self-care assessment, RAS calculations and Direct Payments arrangements.
- c. External quality assessment of service (provided by CQC) as well as Local Authority qualitative feedback (e.g. which services the authority uses)
- d. Customer comments on services, such as 'I want great care' for doctors
- e. Production of quantitative anonymised data from the systems to assist commissioning and service development.
- f. Standards for the transfer of information to the citizen in such a way that they can hold their own social care and health information and share it appropriately.

Consultation questions – Chapter 2

Q6: As a patient or service user, would you be interested in having easy access to and control over your care records? What benefits do you think this would bring?

In social care: Control

In health care: Access

Q7: As a patient or service user, in what ways would it be useful for you to be able to communicate with your GP and other health and care professionals on-line, or would you prefer face-to-face contact?

The nature of social care means that in complex cases, especially with confused and vulnerable citizens, face to face will still be needed as an [option](#).

The option to [email](#), twitter, facebook, SMS or MMS your social worker, link carer or support will be important. Young people and younger adults with disability will find these options very useful, as will many older adults.

Obtaining test results and reports or assessments of care online will be important to enable family members to [share information](#) quickly with accuracy to support loved ones in making good decisions about their care.

Q8: Please indicate any particular issues, including any risks and safeguards, which may need to be taken into account in sharing records in the ways identified in this consultation document.

Ensuring that information kept by the citizen in the information systems is held with adequate security, protected from cyber targeting, and can be communicated and shared safely. Good information governance standards, including easy to use and easy to understand

mechanisms for giving and withdrawing [consent](#), will be essential for protecting the rights of citizens, and enabling information to be used and shared both legally and ethically.

There is also a need to ensure that the accuracy of the record can be owned and guaranteed by the citizen when it comes from multiple sources.

Q9: What kinds of information and help would ensure that patients and service users are adequately supported when stressed and anxious?

A personal level of support, which can mediate information and care provision for both citizens and their carers

Q10: As a patient or service user, what types of information do you consider important to help you make informed choices? Is it easy to find? Where do you look?

Support in understanding my needs and the services that might help address them

What services are available to support my care needs in my locality

What flexibility I have in the financial support available and in using more ad hoc services.

Formal quality control information about services (linked to the marketplaces as a web service)

Informal user information about the quality of services

Q11: What additional information would be helpful for specific groups - e.g.?

- users of maternity and children's health services;
- disabled people;
- people using mental health or learning disabilities services;
- the elderly;
- others?

Each group will have unique information needs and may have varying capacity to handle electronic information successfully and require support/advocates for this.

Q12: What specific information needs do carers have, and how do they differ from the information needs of those they are caring for?

Carers need to be informed about services in place to support them, how they can access and use those services, and what financial support there may be available. They also need information on the appropriateness of such services, and support for the self-assessment of their own needs. They may also benefit from access to forums where they can share experiences and seek advice from fellow carers.

Young carers may particularly benefit from information for them as young people, and not just from a caring perspective.

It is also noted that carers may need to operate a personalised record on behalf of the service user, with concomitant needs to ensure that the service user is in agreement with what is done, and protected from abuse. In some areas of cancer survivorship and some long term conditions there can be very specific issues around information and who has access to it.

Q13: What are the information needs of people seeking to self-care or live successfully with long-term physical and mental health conditions and what support do they need to use that information?

In adult social care terms they need to be able to share the information on their condition (and its prognosis) and the social care needs it creates with those supporting them to create a personal care package. Access to information that assesses the [benefits](#) from particular types of care service, linked to their specific condition will help them make informed decisions when planning their care, along with feedback from those with similar conditions.

Consultation questions – Chapter 3

Q14: What information about the outcomes from care services do you (as patient, carer, service user or care professional) already use?

Q15: What additional information about outcomes would be helpful for you?

Q16: How can the benefits of seamless and joined up information be realised across the many different organisations (NHS and non-NHS) a service user may encounter?

There is a significant danger in trying to provide completely seamless data, without also creating increased complexity (as well as the problems of managing change) that the citizen can not understand. Furthermore there are some services that do not lend themselves to being joined up with out compromising citizen's rights i.e. holding personal bank details on central systems.

Q17: For which particular groups of service users or care organisations is the use of information across organisational boundaries particularly important?

The market for social care services is essentially national, with regional and local variations, which can be easily handled by postcode filtering. Specialised services for specific client groups and the movement of need to be taken into consideration.

18: What are your views on the approach being taken and the criteria being used to review central data collections?

The approach to data collections on outcomes is strongly welcomed, but may need a more research approach to handle the fundamental challenge that outcomes are to more citizen choices than scientific/medical successes. However in respect of monitoring and developing services locally we propose the use of data derived from the proposed market places. This would be derived from transactions carried out in the various markets and thus would capture information on self-funders which is missed in present collections. Services commissioned outside the market systems will be missed, but could be estimated through sampling.

Q19: How could feedback from you be used to improve services?

The focus should be on research work to develop advisory information, identifying successful pathways that citizens may choose to follow.

Q20: What would be the best ways to encourage more widespread feedback from patients, service users, their families and carers?

We propose that the markets have feedback mechanisms along the lines of Iwantgreatcare, tripadvisor and eBay. In addition quality information from both CQC and Local Authorities would be available.

Q21: What are the key changes in behaviour, systems and incentives required to make the NHS and adult social care services genuinely responsive to feedback and how can these be achieved?

In adult social care:

- encouraging suppliers to work through electronic market places;
- enabling and encouraging citizens to hold and control their own record;
- enabling professionals to see the citizen's record as the central record, and configuring their own work around this

Q22: Which questions, if asked consistently, would provide useful information to help you compare and choose services?

Price (which may include locally negotiated contract discounts), service specifications, advisory information and user feedback

Q23: What will help ensure that information systems - and the data they collect - are appropriate to support good commissioning at different levels, including decisions by citizen patients, GP practices, GP consortia, service providers, local authorities and the NHS Commissioning Board?

The key element here is to capture what self-funders and direct payment recipients do so that a better overview of the whole market is provided. In some recent surveys the growth in use of personal assistants, (has been the most significant shift). Understanding and responding to such changes is critical.

Consultation questions – Chapter 4

Q24: How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?

If the suggestions above are taken on board; the responsibility and accountability for data is then transferred to the citizen or care suppliers, and the aggregation of this data will be more difficult. The role for the social care professional will change to then supporting the citizen in their new responsibilities, as well as also being responsible for recording any professional actions.

Q25: As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible care and advice? What could be done better?

Adult social care depends more on citizen choice, so the **concept** of the best possible care becomes an advisory function. The focus is thus on clear advisory information on what is available, what other users have thought about it (relevant to health as well), and what evidence of good outcomes can be provided by research.

Q26: Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically. How can this be facilitated and encouraged? What will be the benefits for staff and what would encourage staff to reap these benefits?

In the predominating business model of self-care and supported self-care the key responsibility for data will rest with the citizen. There will of course be exceptions where the authority takes on this role, notably in cases of deprivation of liberty, adult protection and complex cases where the support network is not adequate. But in all these instances the recording is carried out on behalf of the citizen and to the standards they would attain and can understand.

Q27: What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?

In the new environment most 'casework' information is generated by citizens and held by them and only shared with an authority when required. In informatics terms this means a ceding of data control. The simplification and greater standardisation of existing assessment tools in close co-operation with the citizen will be necessary to enable the citizen to engage in their own self-assessment and care planning, although information will probably be shared largely at document level. This will need to engage stake-holders like GP Consortia.

However three major areas of development do arise:

- The need to understand and analyse data from the proposed market place services.
- The ability to link this with survey and outcome derived data.

- Greater emphasis on research to improve systems and approaches. This may be as subtle as changes in self-assessment tools to focus thinking on reablement or alternative services such as telecare.

There is a need to encourage and develop informatics expertise in this area to support the on-going development of citizen focused information services, to develop and maintain information standards and to provide expertise in [information governance](#) and e-safety.

Consultation questions – Chapter 5

Q28: The 'presumption of openness' in support of shared decision-making will bring opportunities - but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a services user?

How to enable professionals from many disciplines to collaborate in the citizen's own record,.

Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?

We propose that the e-services under development need to be inspected in the same way as traditional face-to-face services. This should provide a network of assured services. Citizens will always be able to go outside these assured services, but caveat emptor as always applies.

Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and 'intermediaries'? Would factors such as cost and bureaucracy outweigh any benefits?

We consider that the accreditation of the market place for services is critical, especially since they will be holding highly sensitive information. The development of specialist portal services, as with Mumsnet etc, would need to be considered.

Q31: How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and can not access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.

We believe that face-to-face and hard copy (letters/invoices etc) will need to be retained in the foreseeable future. At a simple level if someone wants to keep their own records in hard copy this should be feasible. In some cases a professional or carer may need to act as a technological intermediary to enable the citizen to benefit from retrieving information from electronic channels

Q32: Are there other datasets that you think could be released as an early priority, without compromising citizens' confidentiality? Would there be any risks associated with their release - if so, how could these be managed?

The sort of datasets implied in this response are less important and less easily created when citizen choice and citizen record control are in place. In many ways the prime dataset is the marketplace material itself, with its citizen comments,

Consultation questions – Chapter 6

Q33: The information revolution can deliver many improvements. What are particular benefits or other challenges - including sustainability, business, rural or equality issues - that need to be considered in developing the associated impact assessment?

There are three critical issues in delivering a sustainable information revolution:

- a. Ensuring a continuing source of funding to ensure that the systems and services developed can be maintained and continually developed to meet changing needs.
- b. Ensuring a degree of competition between the market place services so that there is a natural driver to develop the services.
- c. Establishing a governance structure that can respond to the inevitable changes in services and care options that research and practice will provide over time.

Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?

Although the response is largely about the creation of a different base of information systems for adult social care, there are the current systems that will still need to operate in parallel, until the new citizen based systems is in place.

There will also be the need for the creation of standards for key moments of interface:

- From a citizen's assessment tool into a resource allocation system
- To confirm a care plan
- Potentially to deal with financial transfers between the local authority and the citizen – to pay for care, and to receive citizen contributions
- To transfer material securely from health or social care professional systems to the citizen and expose the material to those the citizen chooses
- To allow professionals to work together on material in a citizen's own record to help them create their preferred care plan
- To receive information from the citizen's system so that the local authority providing funding is assured of the effective control (including review) of the care plan by the citizen
- To enable non-professional support to the citizen to play its role in all care planning and review
- To enable the citizen record and care to be appropriately managed and secured in case of potential abuse.

A final comment.

These responses attempt to envision personalisation within systems and are a radical departure from elements of the Information Revolution and the gearing up of data to show the success of treatments and organisations in delivering those treatments.

There has been a trend towards this in adult social care, with the introduction of large-scale social care systems, to manage the delivery of care within a Local Authority. There will be Local Authorities that will wish to sustain this approach, and can see the data links with health and other care services that would continue it (although these have been somewhat restricted by the limitation of the Summary Care record, so that such links will be expensively from many systems to many systems). There is a choice at this moment between the following two options:

- Option 1 - An increasingly **data-driven approach** would neglect the control of care and budgets by the citizen themselves and be relatively expensive and complex to push to a successful conclusion (if indeed that is possible). It requires joining systems together and creating much greater commonality across systems so that data benchmarking is possible, and makes the citizen a receiver rather than creator of information recorded about them.

- Option 2 - An increasingly **personalised approach** ceding information control to the citizen pre-supposes the ability of the citizen (and their support) to take such control in the case of information about their own needs and care, which is not yet true of the elderly population which receives a lot of adult social care. It also potentially includes all those who arrange their care privately by stimulating a marketplace for care, and could therefore improve the global information base. It would require work to look at how current freely available software could be tied together with necessary work already under development in multiple places (around resource allocation systems and marketplaces)

We do not believe both options can be followed especially within the current economic climate (although Option 1 can continue on current systems where care is delivered or controlled within a Local Authority).

While we recommend Option 2, we reproduce below some of the comments that have been sent in from ADASS professionals along the lines of a more data oriented approach, which begins (and only begins) to show some of the investment that this would need.

Appendix Comments from information /data specialists working in Adult Social Care.

Chapter 1

Q1: What currently works well in terms of information for health and adult social care and what needs to change?

The PAF, National Indicators and CQC self-assessment measures have worked well in the past to show senior managers how to ask searching questions about the quality of service provided by their organisation. They are not perfect and can have negative consequences. However, they have been a useful starting point.

But, moving forward, there needs to be a few national measures to check progress with national strategies, such as the Dementia Strategy. Local Authorities could benefit from measures that allow benchmarking to be undertaken for key services, such as Self-Directed Support, Carer Services, Safeguarding and Reablement.

Q2: What do you think are the most important uses of information, and who are the most important users of it?

The public are the most important users. Some messages can be powerful, such as recent revelations about which NHS Trusts are most likely to give you an amputation. Simple and stark messages like this can help transform a service.

The next most important are first line managers, middle and senior managers. They need information to show that their service is operating effectively, efficiently, within budget and with good outcomes for the service user.

Q3: Does the description of the information revolution capture all the important elements of the information system?

Yes, it does.

Q4: Given the current financial climate, how can the ambitions set out in this consultation - to make better use of information and technology to help drive better care and better outcomes - be delivered in the most effective and efficient way?

By reducing expectations of the information that can be made available. Also, by relaxing some of the audit rules relating to validating information. Sometimes, it takes 80% of someone's time to get to the bottom of a handful of defective records. If we can take data directly from systems, despite a few imperfections, then this makes reporting directly from systems possible. We can then concentrate on data quality in the background.

Q5: Where should the centre be focusing its limited financial resources and role to achieve the greatest positive effect?

NASCIS is a very valuable tool. This should be retained and widened to make other info, e.g. HES and NCHOD, more accessible. It should collect data via agreed data collections following the zero-based review. Then it should do some validation checks but ensure that the statutory returns have these checks contained within the electronic forms, to allow local authorities to deal with errors at source. It isn't helpful having to deal with further validation errors up to three times following submission of statutory returns.

Consultation questions – Chapter 4

Q24: How can health and care organisations develop an information culture and capabilities so that staff at all levels and of all disciplines recognise their personal responsibility for data?

When senior managers take responsibility for information and make their expectations clear to workers, this ensures that first line managers develop high expectations for recording information. If this is backed up by supporting data quality reports (preferably via up to date, online reporting tools such as Business Objects and Infoview) with information that can be understood by managers, then data quality can improve enormously.

Regular reports on data quality to management teams can reinforce the message.

Other tools, such as the Tell Us Once information pilot for gathering dates of death via registrars will also help data quality.

Q25: As a clinician or care professional, how easy is it for you to find the evidence you need to offer the best possible care and advice? What could be done better?

NHS health data could be more accessible. At the moment it is difficult to find the data you want and to determine the message held within this. Public Health Observatories make particular aspects of data very accessible.

Q26: Clinicians, practitioners, care professionals, managers and other service provider staff will be expected to record more data and evidence electronically. How can this be facilitated and encouraged? What will be the benefits for staff and what would encourage staff to reap these benefits?

With the end of the Summary Care Record as a means of sharing social care data, there will need to be a standardization of all assessment and care planning tools across all systems if there is to be true sharing of data for the sharing of information and the creation of common datasets. Such standardization work will need to engage data from many systems, and especially those of primary health care – led by GP Consortia.

If the reason for the data recording makes sense to the practitioner, the motivation to record will exist and most people are motivated towards providing the correct record for the citizen.

Some data requirements that feed into national indicators make no sense to practitioners. So the removal of nonsensical indicators will help. Most problems arise from national standards of care being monitored through the RAP Return with complex requirements in order for a piece of data to count in an indicator. Now that this is being reviewed through the Zero-Based Review, it should be possible to enforce recording that makes sense to workers.

That is, as long as the Zero-Based Review doesn't result in yet another RAP equivalent.

High expectations on the part of senior management about recording of ethnicity data and other demographic data will also help.

Management information teams can help by attending meetings of practitioners to show analysis of data resulting from their inputting. By feeding back how the information is used, workers can see the sense in improving recording.

Q27: What are the key priorities for the development of professional information management capacity and capability to enable the information revolution?

1. Retention of expertise during the centralisation of back office staff.
2. Training in approved informatics standards.
3. Local ongoing support and training for managers and practitioners provided by local experts in informatics.

Consultation questions – Chapter 5

Q28: The 'presumption of openness' in support of shared decision-making will bring opportunities - but may also generate challenges. What are the greatest opportunities and issues for you a) as a care professional? or b) as a services user?

The greatest opportunity as a care professional (information services) is to be able to learn from others through benchmarking. The challenge is to ensure accuracy at the point of inputting the data.

Q29: What benefits and issues do you think will arise as a greater range of information providers offer information? How could issues be addressed?

The issue will be that of confusion. If too many providers offer information and the information conflicts, then any messages will be diluted. The solution would be to release the data to

trusted outlets such as NASCIS (NHS IC's own presentation arm) and Dr Foster. But the portal to these would need to be less complicated than is currently the case,

Q30: Would there be benefits from central accreditation or other quality assurance systems for information providers and 'intermediaries'? Would factors such as cost and bureaucracy outweigh any benefits?

Accreditation and quality assurance is key to the success of providing information via information providers and intermediaries. The cost and bureaucracy will not outweigh the benefits. In fact, it should be possible to require an organisation to quality assure itself through established firms of auditors such as KPMG, PWC etc. They have streamlined approaches to auditing that shouldn't be too onerous for a company of information providers.

Q31: How can a health and social care information revolution benefit everyone, including those who need care most but may not have direct access to or know how to use information technology? This might include those who do not have access to a computer or are remote and cannot access the internet, people using mental health or learning disabilities services, older or disabled people or their carers who may need support in using technology, and those requiring information in other ways or other languages.

How about publishing data in newspapers? Most people read a newspaper, especially free ones such as the Metro and London Evening Standard. For learning disability services, information could be made accessible and available in day centres, residential care or printed to the back of any regular communications about self-directed support.

Q32: Are there other datasets that you think could be released as an early priority, without compromising citizens' confidentiality? Would there be any risks associated with their release - if so, how could these be managed?

There is no mention of social care. Social care is a big partner in this work. Why are our datasets not listed? Or is this an indication of the level of importance placed on social care as a partner?

Consultation questions – Chapter 6

Q33: The information revolution can deliver many improvements. What are particular benefits or other challenges - including sustainability, business, rural or equality issues - that need to be considered in developing the associated impact assessment?

The comparisons with stock levels and airline tickets are only helpful up to a point. Retail outlets have obligations relating to the sale of goods and after service. However, social care services have wider obligations towards our service users who are often vulnerable with changing needs. Our relationship with our service users is more complex.

This doesn't mean that we can't apply a "record once, use many times" philosophy. This is helpful for the citizen. However, some recognition of our complex relationship with citizen's should be acknowledged.

For example, a relative may ring about a safeguarding concern. Presumably, this wouldn't then be copied into different systems until it is substantiated. In automating the flow of information, standards for sharing particular pieces of information will need to be developed.

Also, many systems already automate the inputting of data. For example, in Frameworki, the demographic data about a client (e.g. DoB, gender etc) is automatically populated into the forms. If it can be automatically populated from another system, that will be useful.

However, many Local Authorities have already tried using linking software and failed. The main issue is with identifying the citizen. The NHS reference number will be a useful common identifier, which will help. But the ongoing work with matching social care and other systems will need to continue.

Q34: Are there any critical issues for the future of information in the health and adult social care sectors that this consultation has not identified?

One critical issue is that many information services will become a corporate function. There appears to be tension between the expectations of CLG and DH. CLG is looking for reduced datasets. DH is looking to minimise the reporting back to the centre. However, the information revolution places a requirement on local authorities to maintain systems with high quality information that cover a wide and fluctuating range of health and social care information for each citizen. This requires an experienced and adequately resourced information team. There is no mention of continued resources in Local Authorities to ensure that this programme of change management is a success.

I'm still not clear about exactly how the service user is going to have control over his/her record. What will be put in place to do this if it has to be achieved with limited funding? To draw on the retail analogy again, I'm sure multi-national retail outlets and airlines have invested properly in the technology for their systems and not tried to do anything on the cheap.