Improving lives consultation

Centre of Excellence for Information Sharing findings report

Introduction

The Department for Work and Pensions (DWP) and Department of Health (DH) is currently running a public consultation on questions published in a joint green paper on the topic of work, health and disability, entitled 'Improving Lives: The Work Health and Disability Green Paper'.

This report pulls together the ideas discussed during the workshop facilitated by the Centre of Excellence for Information Sharing on 6th February, in order to contribute to the consultation.

Aims of the workshop

- provide participants with an opportunity to think through challenges and opportunities for better information sharing which supports service users' public servants and other partners to improve health and work outcomes;
- share existing good practice, identify what works locally and nationally and highlight key learning for wider dissemination; and
- provide participants with a networking opportunity and potential to build a peer network, this will in turn enable participants to learn from one another's experiences and ideas to achieve success in their own locality.

Barriers to information sharing discussed at the workshop

The need to share information is a universal practice across the public sector. In many cases there will inevitably be barriers to overcome, which, from an internal perspective, may seem unique. The following barriers to information sharing were discussed at the workshop:

- Collaborative working
- Governance and risk
- Service user experience
- Trust
- Shared vision
- Strong leadership

The findings

Some of the key issues which emerged from discussions were:

Collaborative working

From the discussions at the workshop, delegates expressed views that organisations work in silos and approach risk management as an internally based activity.

Trust

The issues which impact on trust in sharing information were highlighted as:

- trust in the data sharing process and in keeping data secure when shared;
- limited trust in partner organisations that request or receive information; and
- trust in managing and mitigating risk associated with information sharing and the potential impact of a data protection breach.

It was felt by delegates that information sharing is often seen as the ‘elephant in the room’ and they intonated that unless there was an explicit benefit to their organisation, why would they put in all the hard work and not reap the benefits. In particular, this emerged from discussions related to consent and the effort involved in obtaining permission to share personal information.

Governance and risk

There was a general consensus from attendees that one of the key concerns was about making informed decisions about what to share. It was also felt that whether there was a legal basis in which to share was still at the heart of managing risk, being symptomatic of a culture of risk aversion.

Shared vision

Delegates felt that organisations working together to create a shared vision and common purpose would better support the joint work and health agenda. Delegates said a good solution would be to develop a model of joint working with a clear shared statement of health and work outcomes.

Service user experience

At the heart of conversations on all tables was the service user experience. Conversations focused on:

- what does consent mean to organisations and service users?
- how is consent obtained and then managed during a service users experience between health and DWP services?

Strong leadership

People in the room said they felt that with the current focus on reducing resources and the increasing demand and expectation of service users on public services that the pressure to ‘just keep the lights on’ inhibits the ability to innovate and develop.

Delegates described how strong leadership is needed from national partners. Good communication and clear messages are needed about what the DH and DWP shared objectives are, in order to support local places to design better services.

In addition, people said that strong leadership at the local level is also key in supporting organisations to develop better local partnership working.

Good practice examples in information sharing provided by delegates

Trusted agents - using trusted services and professionals can get a ‘foot in the door’ and achieve consent from public to share information e.g. Safe and Well Visits, Fire and Rescue Service.

Co-location – the public are more likely to give consent to sharing information in a co-located environment and experiencing coordinate meetings and support e.g. ‘Me and My Learning’.

Embedding - embedding health and employment within each other’s operations e.g. Work Coach in GP surgery, Middlesbrough; employment advice in (mental health) Individual Placement and Support (IPS), North West London.

Case conferencing - approach for individuals with complex issues via multi-disciplinary team information sharing providing full understanding, improved assessment and better sequencing of interventions e.g. Troubled Families ‘team around the family’.

Alerts **-** providing automated alerts and prompts on IT systems to 'remind' professionals to refer and share information e.g. Fit Note prompt on EMIS for GP to refer to Job Retention Service.

Changing mind-sets - providing training for Health Care Practitioners helps to change views on employment and health and shift understanding to one of work as a health outcome. e.g. CCG Employment Lead role.

Creating the local system - securing a health lead to recognising and developing the approach to developing the strategic focus on work in the health system e.g. Islington CCG Health and Employment Programme.

Nb: if you would like to know more about any of the examples provided above, please contact info@informationsharing.org.uk

Consultation questions: responses

The workshop focused on a number of specific questions related to information sharing in the consultation paper. Feedback received from delegates is outlined below:

Question 7.1 How might we share evidence between assessments, including between Employment Support Allowance/Universal Credit and Personal Independence Payments to help DWP benefit decision makers and reduce burdens on claimants? What benefits and challenges would this bring?

Delegates said it is important to:

- Ensure there is a consistent approach to gaining consent adopted across organisations and that the service user is fully informed about what information gets shared and with who.
- Develop a shared understanding across health and work services of what information is needed to support an individual.
- Equip health professionals with an understanding about benefit entitlements in order to be able to signpost service users to appropriate services. Develop mechanisms which support information sharing between different benefits e.g. PIP and Work Capability Assessment (WCA). Have work conversations in care settings (early in the process).
- Understand trigger points that indicate possible interventions that may/could be required e.g. change of address.
- Create a core digital information hub with mechanisms for specific access rights to data dependent on organisational need.

Benefits:

- Simplifying processes could potentially reduce the burden of work and health practitioners.
- Improved referral protocols could reduce delays to benefit claims.
- Service users would not repeat information unnecessarily (e.g. 'Tell us Once').

Challenges:

- The current system isn't joined up so the responsibility falls onto the service user to provide information multiple times.

- Ensuring services work towards developing shared outcomes whether their primary focus be on health or work.
- It's a challenge to integrate social care into health and work delivery.
- Develop the use of the integrated digital care record to share relevant information with PIP and provide a flagging system for referrals.
- Inputting information correctly.
- Establishing and maintaining trust with service users.
- Unify identifiers to record health conditions which are used by different organisations.
- Health care professionals seeing supporting people into work as part of their role.
- Co-designing processes to share information, both locally and nationally.
- The client needs to have ownership of their data.
- Integrating the assessment processes.

Question 11.1 - How can we bring about better work-focussed conversations between an individual, healthcare professional, employer and Jobcentre Plus work coach, which focus on what work an individual can do, particularly during the early stages of an illness/developing condition?

Delegates said:

- To create systems which are flexible and intuitive and allow information to flow between health and work services and be user-led. Including putting in place the right level of appropriate governance and data security provision. Supported by a clear explanation to the client of how this will happen and why this would benefit them.
- It is important that the service user has a trusted key worker to act on their behalf and on behalf of the other organisations providing support to that person. We under-value the importance of trusted services to the individual.
- Partner agencies may be better placed to have work-focussed conversations, specifically where the operational set up is co-located, to support information sharing for assessment and case working. Co-location also helps to alleviate concerns that information is being stored or shared inappropriately.
- Exploring and developing case conferencing could address sharing information about making reasonable adjustments for a service user in the workplace.
- Where appropriate, involvement of the voluntary and charity sector would provide valuable input and advice to a service user. This would involve either earlier input into a work plan or as an advocate for the service user.
- Feedback should be provided to all involved about the progress an individual has made.
- It is important that healthcare practitioners have a 'prompt' to have a conversation with service users for considering what support they need to support them to work.
- To consider a 'social prescribing' model to support and motivate the person to move forward which would reduce the burden on GP's to provide assessments/evidence.
- To offer holistic/alternative support networks to service users.
- To take learning from other initiatives such as Troubled Families.

Question 14.1 How can we best encourage innovation through local networks, including promoting models of joint working such as co-location, to improve health and work outcomes?

Delegates said:

- Innovation can be encouraged by selling the benefits to service users and service providers of not having to repeat information.
- An example given of an innovative approach is where a case leader is appointed on behalf of the service user to work across organisations and act as a single point of contact. It was felt this makes managing consent much easier and can improve the referral process between support services and leads to improved outcome to the individual.
- There is a requirement to further scope and understand the current cultural context of the processes of information sharing and provide further learning to organisations. This will help develop a multi-faceted, multi-directional process of identifying entitlement to other benefits (e.g. a Personal Independence Payment [PIP]) based on information obtained for universal credit claimants.

Question 14.4 - How can government and local partners best encourage improved sharing of health and employment data

Delegates said it is important to:

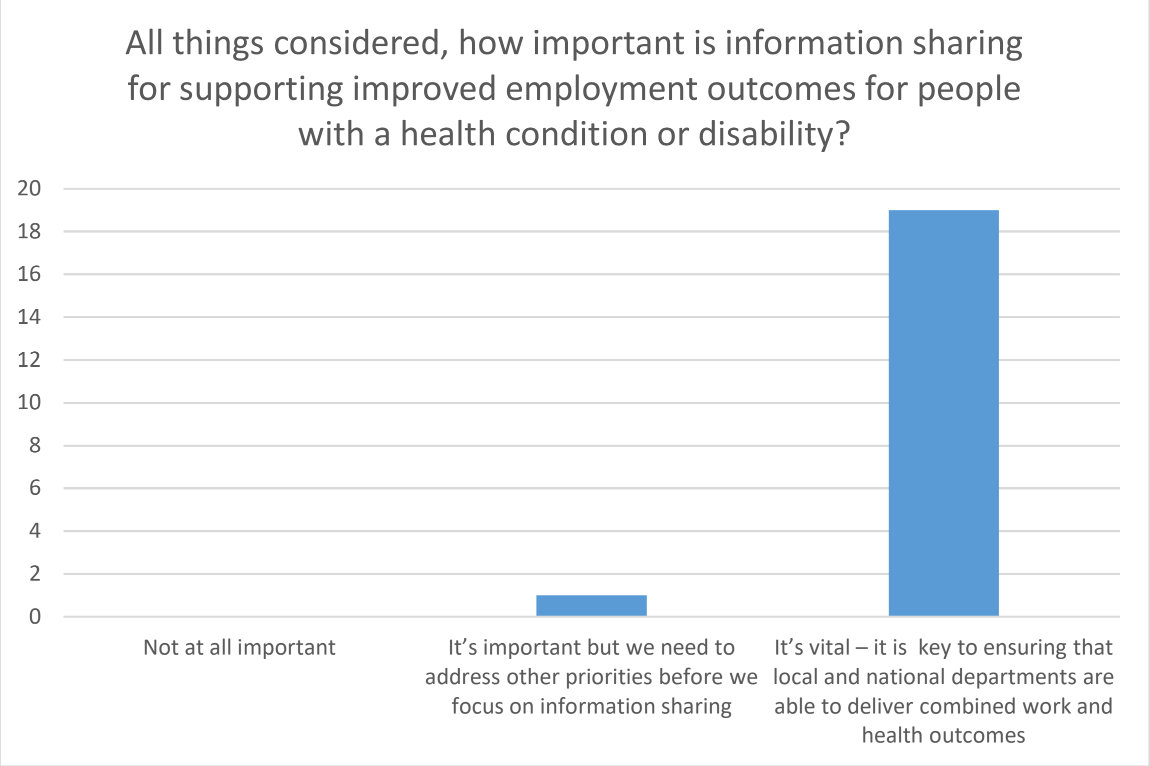
- Ensure employers and employees have access to preventative initiatives such as online wellbeing tools to support people to remain healthy in work. E.g. local strategies such as London Healthy Workplace and Local Authority Community Wellbeing Programmes could be promoted and developed in the workplace.
- Support employers to be able to make reasonable adjustments in the workplace. E.g. using the ‘fit for work’ assessment and occupational health advice.
- Know who holds the relevant information which can be useful to provide the support an individual need. “Nobody knows who’s got what information and therefore nobody knows how to get the right information”.

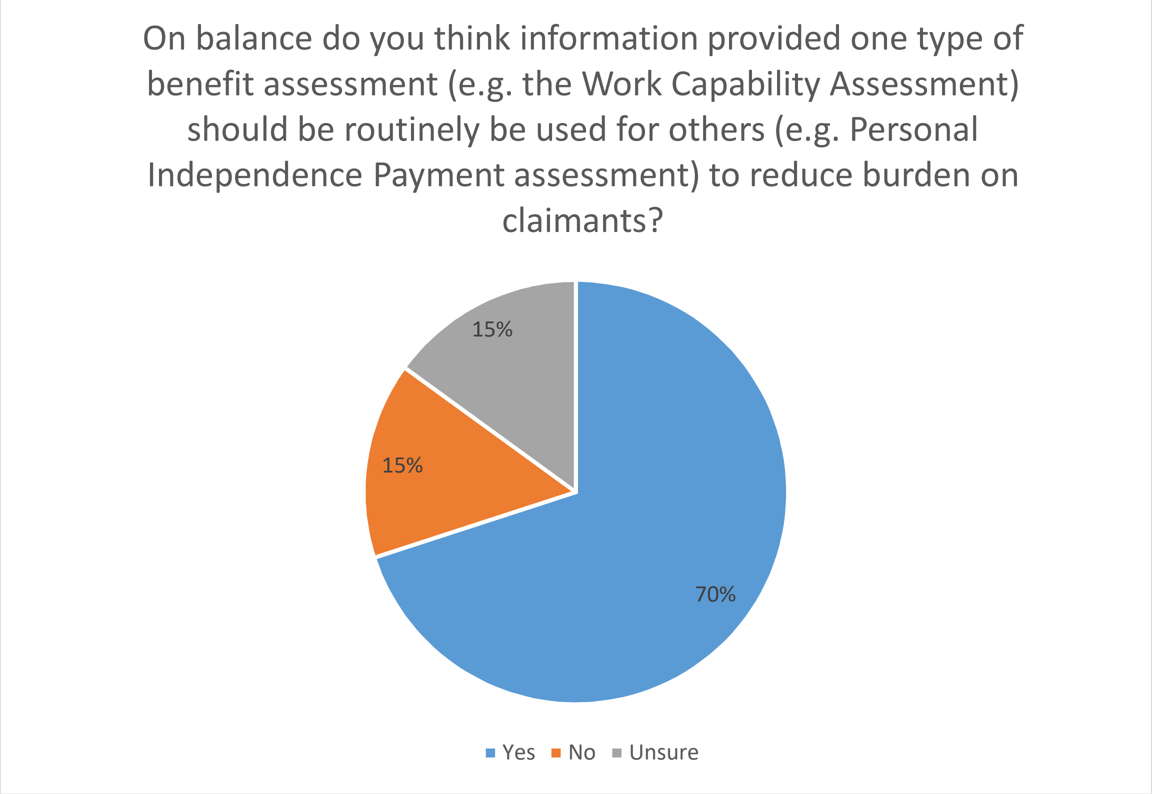
Question 14.6 – What is the best way to encourage clinicians, allied health professionals and commissioners of health and other services to promote work as a health outcome?

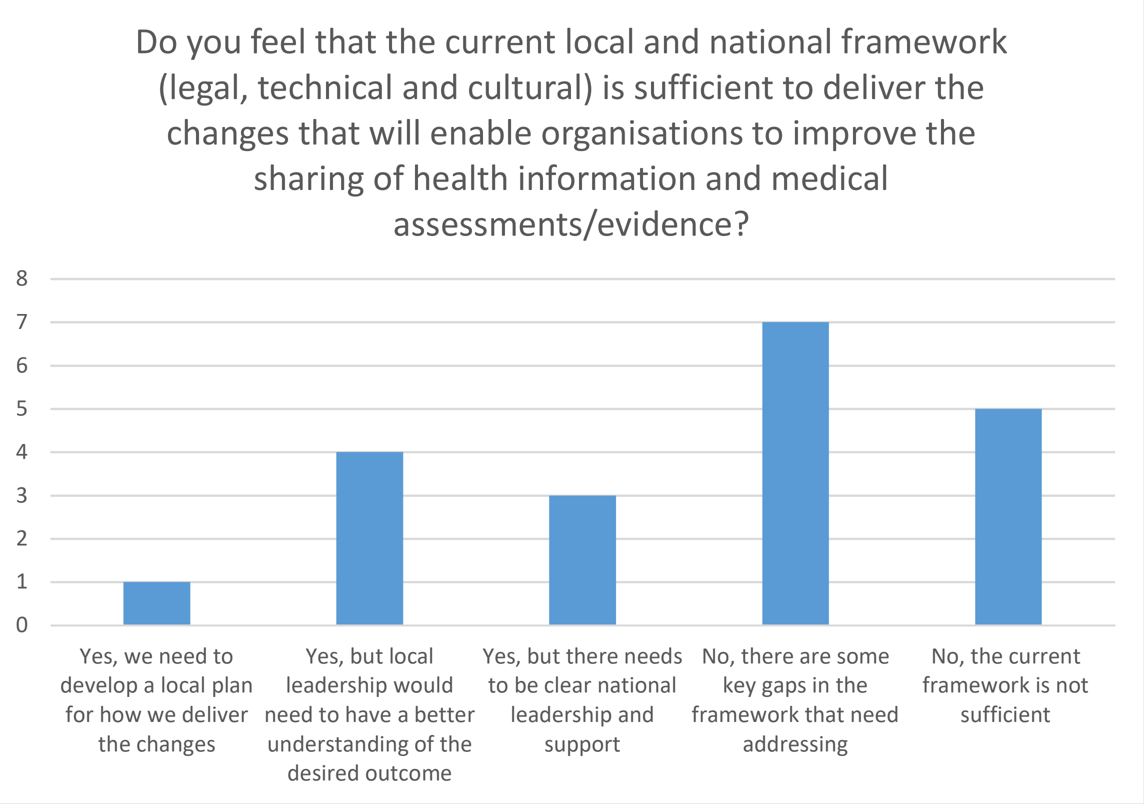
Delegates said it is important to:

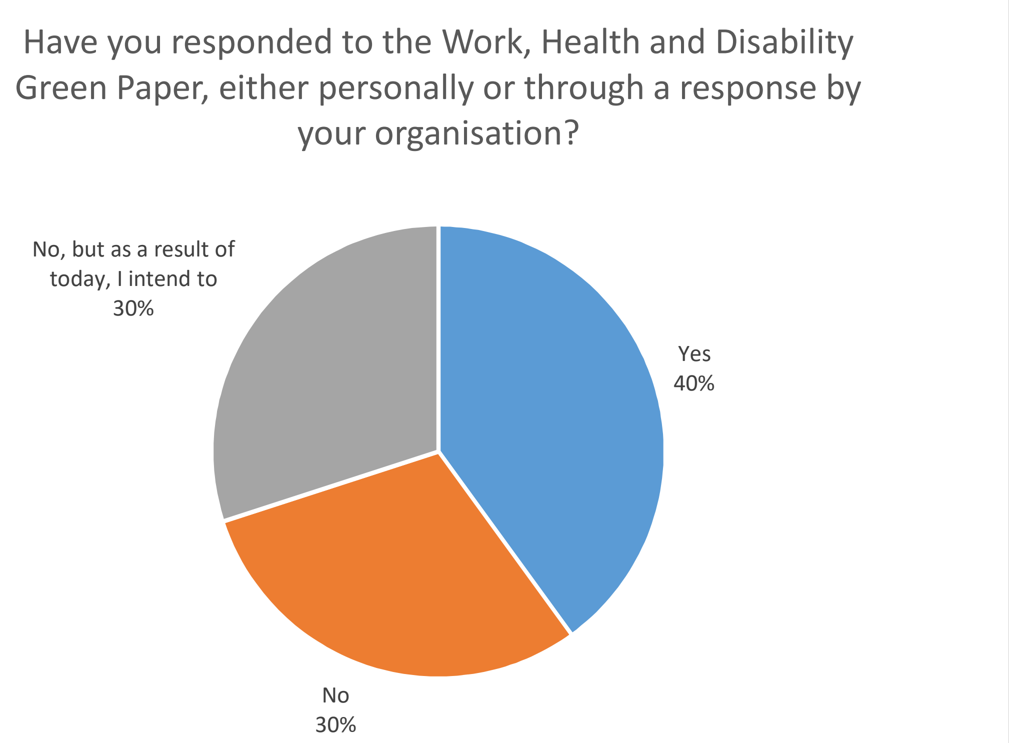
- Build relationships with GPs helps develop better understanding of the demands on services and to develop together shared objectives around improving health and work outcomes.
- Provide GPs with a ‘flag’ system to signify that a patient needs a conversation about work.
- Have greater understanding of the current relationships and communication processes between GP's and Jobcentre Plus’. Asking questions such as “should the burden of health information/evidence only be on GP’s?”, “Who else do they think could provide evidence?”, “Who else should provide evidence?”

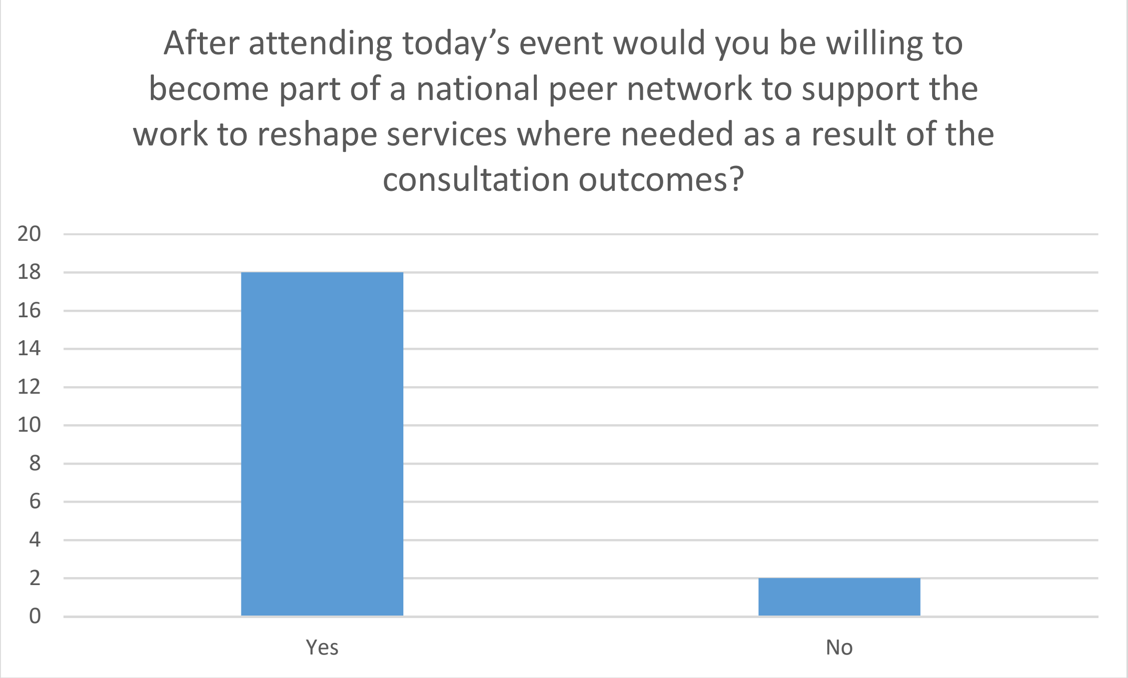
Appendix one: statistical results from voting handsets
At the end of the workshop, delegates were asked a series of quick fire questions to ascertain the mood within the room and gain some statistical analysis to reinforce this. ‘Voting handsets’ were used to gather this information; there were 20 responses to each question.






Do you feel that the current local and national framework (legal, technical and cultural) is sufficient to deliver the changes that will enable organisations to improve the sharing of health information and medical assessments/evidence?
8
7
6
5
4
3
2
1
0
Yes, we need to develop a local plan for how we deliver the changes
Yes, but local leadership would need to have a better understanding of the desired outcome
Yes, but there needs to be clear national leadership and support
No, there are some key gaps in the framework that need addressing
No, the current framework is not sufficient


Have you responded to the Work, Health and Disability Green Paper, either personally or through a response by your organisation?
No, but as a result of today, I intend to 30%
Yes 40%
No 30%



Appendix two: postcard responses

During the workshop, delegates were asked to complete a 'postcard' which was a direct line to government, the question posed which delegates were asked to respond to was:

'Considering what has been discussed today, what key things would you like to feed back as part of the consultation? For example, what actions do you feel national government could take to improve information sharing at a local level?'

The responses to this exercise have been grouped below into key themes.

Partnership working, culture and trust

- 'Changing cultures. Moving away from increasing focus on performance targets which potentially drives behaviours to having a shared vision and ethos. Which filters down to operational level and not just strategic level.'
- 'Please let the customer see their data and allow them to say who can use it for what purpose.'

Service design

- 'We should test a single assessment or further medical evidence process in some CCG's to reduce the burden on GP's.'
- 'Improve/create digital platforms to facilitate data sharing.'
- 'Share NHS data with various departments, local authorities to help people access support.'
- 'Where a statutory legal basis doesn't exist the gov can support by creating regs.'
- 'Implement ICO privacy by design.'
- 'Include appointees/ carers in info gathering process.'
- 'Don't allow multiple teams to try and solve the same problem. Get the right people in the same room.'
- 'Co-ordinate and integrate assessment processes as much as possible.
- 'One assessment "fits" all.'

- ‘Using MI to promote the rise of community services.’

Vision, leadership and governance

- ‘Support health practitioners to view employment as an outcome. Greater support for employers to view health and wellbeing of employees as core to their business and access to occupational health and other support.’
- ‘Take onus off GP's being requested to provide evidence, by making case notes available electronically.’
- ‘Less reliance on GP info.’
- ‘Identify strategic leaders across local systems who can own and lead this agenda.’

Professional development

- ‘There are overarching principles for information sharing: what info is required? Do I have statutory basis to request it? Who is the data controller of the data? Is the patient aware of data sharing?’
- ‘Gov need to ensure organisations are clear about their responsibilities and have confidence in their ability to request data.’

Make informed decision, managing risk

- ‘Ensure citizens are aware of organisations intentions and promote trust between citizens/ and orgs holding their data & between orgs and who want to share data.’
- ‘Stop talking, allow a team to see how far they can get with consent driven data sharing.’

Political positioning

- ‘Financial constraints lead to risk averse decision making in local authorities. This stifles innovation and the evaluation of novel approaches. Information sharing tends not to be business as usual or statutory, and is therefore very low priority in resource scarce departments such as adult social care. Targeted funding/opportunities for pilots and evaluations would really help :-)’
- ‘Give local organisations the space and funding to innovate.’
- ‘Financial constraints lead to risk averse decision making in local authorities. This stifles innovation and the evaluation of novel approaches. Information sharing tends not to be business as usual or statutory, and is therefore very low priority in resource scarce departments such as adult social care. Targeted funding/opportunities for pilots and evaluations would really help :-)’
- ‘Consideration needs to be given to SME take up of retention initiatives such as occupational health. Many will not be aware of the support available and will be hesitant to shoulder perceived cost.’
- ‘I would like to see locality based targets so that all organisations are working towards the same goals - this will impact on commissioning and promote better information sharing - it provides the incentive and rewards!’
- ‘Create shared budgets across work and health - employment costs can be considered to be part of an overall budget - as it must eventually be at treasury level.’