

**Patient Revolution – 11 June 2014****Transport between Haverhill and West Suffolk Hospital**

- Buses stop at 1730, leaving no access evening
- There is no Sunday service
- Buses drop off by Tesco Express, leaving a long walk to WSH – could they divert to the hospital?
- People may not be aware of accessing Suffolk Link to provide transport? Leaflets and posters available
- Support is given largely to patients who chose to go to WSH as opposed to Adenbrooke's.
- Not equitable with other towns, such as Brandon
- Haverhill people would value being able to access other services Bury St Edmunds has to offer as a town, which makes a stronger case for improved transport
- Patients choose Adenbrooke's because they perceive it as the only option due to transport
- Haverhill would benefit for a health centre similar to Sudbury. The population is set to increase over the coming years
- Out Of Hours/emergency access to WSH is difficult in winter due to poor road access – most patients go to Adenbrooke's
- The Crown drop-in centre in Haverhill closed as the Government initiative stopped
- Outreach clinics in Haverhill and use of telehealth solutions, such as follow-ups, would help improve patient experience

Joint Commissioning for Neurology across Suffolk

- Adopt quality neurology audit recommendation
- Revisit Suffolk Community Health neurology business case
- Work with Suffolk County Council on integrated care for neurology
- Adopt integrated care pathway for neurology
- Embed neurology in the joint strategic needs assessment
- Work more closely with the voluntary sector (neurological network)
- Remove the east/west Suffolk divide
- Increase neuro specialist rehab
- Increase GP referrals to Abbeycroft Leisure for rehabilitation

Meeting the needs and shaping services for family carers of black and minority ethnic (BME) origin and mental health conditions**Challenges**

- How is trust, rapport, services, etc, established with group that have a diversity of needs/cultures, such as Romany Travellers needs differ from Gypsy travellers
- Remember, family carers are experts
- GPs need a better understanding of mental health conditions and to recognise signs
- The CCG needs cultural awareness and would benefit from involving/linking with groups – just because west Suffolk has a low percentage of BME groups does not mean that CCG commissioned services should not be educated about BME groups' needs
- CCG should ask questions to find solutions
- Start where carers and people are



integrated working

- CCG to promote the positives of family carers and help and engage people to recognise they are carers
- Use carers' expertise, knowledge and skills to shape services
- How do health services reach the 'unseen' carers
- Use 'officers on frontline' expertise to engage with groups – feed into CCG policy and process
- Schools and the clinically trained need to have knowledge/attitude to better understand and have awareness of young people, BME, and other cultures' needs in dealing with mental health issues

Mental health and promoting wellbeing

- Discussions need to be had to raise awareness of mental health in schools
- Teacher support
- DVDs, such as from Suffolk User Forum, could be used
- More psychological input/talking therapies
- Increase/promote recovery colleges and peer support
- Promote therapeutic activities including art, singing and exercise
- There should be a director of well-being services who is available to all, and a register of accredited therapists
- Greater access at early stages – improving access to psychological therapies (IAPT)
- Assistive technology for some people – support via video conversation
- More creative referrals from GPs – for example use not only gyms, but link with Ipswich Football Club too
- CCG/county council website – link to hub with details of services
- Conference to link all services
- Gender balance, for example having men's health groups as well as women's

Mental health management

- Mental health care in Suffolk is improving
 - Recovery is management
 - Shared
 - Coproduction
 - Service user involved in recovery
 - Acceptance, responsibility, management, satisfaction
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- Recognise crisis and allow a step forward without going backward.
 - Greater all round contact after needed after it is initially made, such as seeing a link worker more than once a week
 - Avenue to accept mental health change with age
 - Management
 - Have a link worker to flag up backwards steps
 - Misuse of link workers
 - As part of service redesign reducing beds, are patients being discharged too soon? And to where?
 - Continuity of care – even though you are signed off you should be able to be picked up from the last point
 - Access and assessment are not meeting needs. It is time to change and reduce stigma
 - Stigma on professional level



integrated working

- Service users have low level of attendance because they feel things do not get acted on after, and it is therefore more lipservice

More money and resources into adult mental health services

- To provide better service to clients so they can improve quality of life to best effect
- To lessen stress effect on overworked front line staff with very large case loads, resulting in less time for clients:
 - Staff burn out
 - Dissatisfaction with mental health providers has increased
 - Too many managers, more front line staff?
- Enable easier access to voluntary sector. Does the CCG and GPs know who they are?
- More referrals into referrals service from GPs to adult mental health services
 - Waiting list too long
 - Takes too much time
 - More staff needed
- Results – client's stress increases and family carer's stress increases while waiting for outcomes/treatment
- Self-referral for clients
 - Face to face meetings can be stressful.
 - Can they access referral /services via email? Website info?
- Education on mental health is needed in schools/work places – further information via website, big advantage when someone wants information but does not want peers/family to know
- Website has general information on services and this is needed for wellbeing, self-help, etc

Improving physical health for patients with mental health:

- Provided fitness staff have the training they can give anyone a plan to follow
- There is specialist training for anxiety, depression, post operations, etc
- Exercise can boost morale
- A scheme has been in place for 3 years
- At first, benefits of physical exercise for mental health were not understood – this is gradually changing
- No brainer – £300 for medication or £50 for gym
- Should be a special rate for carers
- There are all sorts of institutions who manage mental health and given special rate to use facilities
- Help integrate people
- Friday club – come in gym

Improved Physical Health Care for People with mental health problems

- Chronic Pain Evening on July 3 – detail was given to staff or e-mailed to those who may be interested
- Nobody recognised a health issue and mental health issue
- It takes two years to sort out
- Cognitive behavioural therapy nurse and psychiatrist is at Newmarket
- Time taken and different people spoken to until right diagnosis
- No joined up physical health and mental health



integrated working

- Support groups – go there and gain support
- Post GP referral scheme – come down and have a chat with like-minded people
- Why is there not a community board in Kingfisher?
 - Could this be something that is set up?
 - Come along via leisure centre – other groups can attend
- Support people in homes and in their own homes
- People are not being diagnosed early enough
- After attending GP surgery the issue is not taken forward as a physical problem would be
- Parity of esteem
- What should GPs do?
 - Stigma of mental health
 - Some GPs have more knowledge
 - Have GPs got time for appointments?
 - It is difficult to discuss in 10 minutes
 - GPs cannot see what goes on inside the person
 - Continuity of care is important – GPs know the patient
 - GP retirement and moving on – worries that the new GP will not know enough
 - Time taken may be thought wasteful
- Mental health drugs – worries that they are not reliable/poor quality
 - Do GPs know what drugs a patient is taking?
- GPs are not interested and tell people to see a specialist
- Clinicians have their own agenda and you can get lost in their knowledge
- ‘I had to fight long and hard for the right to get education on my condition’
- When you get a copy of a letter to the GP it is really interesting
- GPs get patients mixed up and paperwork is a nightmare
- Not everybody gets a letter after a consultation – a letter could be e-mailed to the patient at little cost
- Improving physical healthcare for people with mental health problems – maybe there should be a system where notes follow the patient?

Late referrals to Crossroads – people referred from continuing healthcare

- Provide funds to Crossroads to provide care. Often referrals are received when a patient is very close to death
- If a person dies over weekend Crossroads cannot contact continuing healthcare
- Who commissions continuing healthcare – local authority or CCG or providers?
- There needs to be a pathway to ensure continuity over weekend
- Raise awareness with general public and with health and social care professionals
- Good practice GPs have discussions
- Perception of ward hospice
- Awareness raising could be coordinated with CCG, St Nicholas Hospice Care and others
- Care navigator/co-ordinator could help ensure people are aware of services available to them
- How do we bring that information together?

‘Butterfly conversation’ – More responsive user-friendly complaints system



integrated working

- A better feedback mechanism is needed for people for people who want to highlight things which have gone badly (or well) but do not want to make a formal complaint
- More responsive so person feels issue has been listened to

The relationship between the CCG and voluntary support organisations

Does the CCG know who these groups are?

- Upbeat, heart support groups, exercise, heart monitoring, etc.
- Mid Suffolk AXIS, day case sensory and physical disabilities
- Suffolk County Council, adult social care, community
- Befriending schemes, for vulnerable adults, drop in services
- Age UK Suffolk, falls preventions service

Comments

- It was hard for agencies to get stalls placed at Patient Revolution, but this showcases what services are available
- How do general public get to know about voluntary services?
- Voluntary services are often qualified to do excellent services. Is this recognised by the CCG? For example, cardiac nurses are employed by Upbeat to monitor group members
- Suffolk County Council has a website for voluntary groups info – 'my life' info
- More education needed to inform CCG of voluntary agencies work
- How to communicate? Should the CCG visit voluntary groups?
- Employing a resource to work proactively with voluntary groups to liaise/inform
- Target 'pots' of money/funding towards voluntary sector as identified by public and voluntary groups
- Good relationships with GPs, CCG and voluntary groups are essential to deliver services to people from all resources available
- Is a partnership approach being adopted?
- Focussed group meeting on objections from voluntary sector to see how they can assist with specific objectives – targeted needs/services
- Both Suffolk CCGs and the county council could meet and recognise voluntary groups, talking to people who run services and use them.
- Show what a difference voluntary sector makes to people's lives
- CCG/voluntary sector showcase support once a year for general public/members, such as around heart conditions, stroke, mental health, etc.

How can CCG work with Vol. Sector to improve admission prevention (mental health)

- Clarity needed around what admission means and consistency access Suffolk
- Gap between hospital (A&E) and support needed if person is not admitted to hospital
- Individual response needed – partnership work with strategic and voluntary services to ensure consistent approach to service user
- People who deteriorate rapidly are likely to be known to service already
- Admission can be positive
 - Alternatives such as phone and community support
 - Short admissions can work
 - Discharge plan is important
- Service users fear how to re-access services quickly
- Gap between services and 'recovery'
- Crisis planning/knowledge of resources
- Service users need to know where they can go



integrated working

- Community services directory needs regular updating
- CCG neighbourhood teams – re-promote these with voluntary organisations attending
- Out Of Hours crisis support – resource is too limited
- More mental health training for voluntary services whose main focus may not be mental health
- Lack of provision for children and young people
- Shortage of move-on accommodation from supported housing, particularly in Bury St Edmunds
- Prevents people moving through pathway quickly enough.

Cost of hospital parking

- Too expensive
- Professionals and patients
- Discriminated against if sick
- Compare Papworth with WSH – Papworth is better organised
- Run by external organisations – profit should go back into the NHS, not a private company
- Competition creates problems
- Not very many disabled bays, some see this is discriminatory
- Connected transport services are essential – how do patients get from a large car park to where they need to be?
- Affects carers and families too
- People with eyesight problems often have physical problems too – how do they get from the back to the front of the car park?

Early recognition of mental health

- How do GPs train to recognise mental health issues?
- Early diagnosis is essential
- Need better signposting and directions to support groups
- Important to have a GP who knows you
- Medicine is becoming holistic
- Knew nothing of Abbeycorft Leisure referral
- A lot of GPs fail to promote, even in own surgeries
- GPs seen as first port of call
- Mental health should not have to be a long road to go down
- Primary care staff need education
- Mental health must be de-stigmatised
- Services must be accessible
- Attitudes developed and skills learnt during adolescence
- Need safe environment and enduring relationships
- Can ultimately lead to homelessness
- Time to access bereavement services is ridiculous
- GP should recommend Cruse not Wellbeing

How can we better engage with the people of West Suffolk?

- How do we sustain change?
- Some CCGs use patient participation groups as a key communication group
- Embed engagement in our culture



integrated working

- Tie up with shared decision making
- The CCG can do more to engage whole community, such as hard to reach groups.
 - The CCG needs to go to them
 - The CCG should see ambassadors of large groups (10,000 plus)
 - We must recognise that groups are different
- People have the right not to engage
- Refugees and asylum seekers:
 - Fears and loss need to be recognised and supported.
 - There should be a contract for dealing with hard to reach groups (as in south east Essex)
 - People should be identified and signposted
 - There needs to be data for the population of west Suffolk
- Take care not to duplicate
- Local community wants to be treated as such – for example not west Suffolk, but Haverhill
- Directory of services and high demand for this
- Services not aware of each other as they are not connected
- Information needs to be kept up to date – is there an IT solution?
- Care coordinator to support people and help them access the right services
- Change skill mix in primary care to handle current and future needs
- Integrate primary care with other services to reduce demand on GPs' time
- A community bus for young people offering drop-in service to discuss problems was provided by the county council but has now been withdrawn
- Forms for idea sharing by providers – the council is doing this with some initiatives
- Provide bus to pick up/go to hard to reach people – soup kitchen/tea, cake and chat bus
- Increase use of social media/YouTube films
- Information via food banks for hard to reach people
- Events like patient engagement held at weekends to increase access
- Education offered via libraries. Audio tapes, TV, radio, leaflet drops, and megaphone announcements on buses

Residential and nursing homes

Care Homes

- Effective training provision for staff – could be done at GP practices
- Administering first aid not happening
- Oxygen therapy when needed for sudden illness is not administered by nursing staff
- Moving and handling, falling falls
- Training standards to be part of commissioning contracts. This should then be monitored
- GP practices to be hub for training and support for care staff
- Consistency of care provided

Admission and Discharge

- Integrating urgent, primary and secondary care pathways
- Could there be a trip adviser approach to care homes? This could be a highlighting tool
- What happens to information? Is it acted on? What are the trends and themes?
- Rights of view/entry – approach to view care in action

Out Of Hours

- The 111 service is frequently used by homes
- Medication is being issued by OOH following discharge
- There is a 'ward round' approach so there is one visit per home, not multiple
- Education of home staff should be given regarding the use of 111



integrated working

The consumer voice needs to be heard more.

Three ways to address issues:

1. Improved communications between providers and stakeholders, including the consumer voice
2. Mandates for training standards by commissioner – involve health and local authority commissioners
3. Nominate a champion in each care home to understand locality issues

Care home open days are not supported by the local authority or CCG

Awareness and knowledge of Osteoporosis

- The GP is important, particularly in distributing information, with diagnosis and drugs
- Need link nurses
- Clarification of implications
- Importance of correct exercises – Pilates, walking, tai-chi, etc
- Promote wellness, improvement – and mobility
- Access DEXA scans at correct interval
- More education on osteoporosis needed for GPs
- Link with Abbeycroft Leisure for booklet/info on exercises to maintain/increase bone density
- Need a publicity drive

Health professionals should listen better to patients

- Health workers are coming to conclusions that are wrong
- Difficulty of access to GP
- Patients know themselves
- Use language that is understandable
- Need feedback process for health:
 - How do patients make themselves heard?
 - How do we find out what we could do better?
- Patients feel they will be sidelined if they complain
- Health workers are too focused on following pathways instead of listening to patients
- Health should be tailored to the individual. Excellence can only be established through feedback. People do not like to create fuss
- Too many visits and seeing multiple departments. Did not complain as coming to Patient Revolution, but this is only once a year
- Traffic light feedback:
 - Green – What did we do well?
 - Amber – What could we do better?
 - Red – What should we do better?
- The system must be prepared to change
- Let common sense prevail over systems and pathways
- Empower patients to take control
- Let patients be the owner of their own record:
 - Patients should be involved in pathway design
 - Ask those on pathways or those who have used them
 - Start design at – ‘What would be an ideal world?’
- Health professionals must not make assumptions
- Things are being done twice because they are not done properly
- Just because the NHS has a monopoly it should not be excluded from patient evaluation



integrated working

- Safe way to report – family, neighbours, individuals, etc
- Ineffective social care can affect health care
- Get social care right and this can reduce healthcare
- Friends and family tests are useful as feedback needs to be anonymous
- Waiting times in outpatients
- Patients are unable to understand the specialist
- Patients need to be able to listen to the clinicians
- Nurses chat and stand around while patients are anxiously waiting
- Patients cannot understand foreign doctors
- Personal discussions are taking place among staff which are unrelated to clinical care

Disability and discharge from hospital

- People are discharged during the night
- Patients end up with insufficient medication as pain management had not been thought about
- Post triple bypass a patient was discharged with nothing set up at home – what systems can be put in place?
- Planned – seems to work well
- Unplanned – often too rapid and things not in place
- Feeling unwell/vulnerable/unable to make decisions – often reach crisis point
- Age UK is able to offer support – is the charity involved with all discharges, planned and unplanned?
- Medication
 - Post discharge, a minimum amount is given by the hospital.
 - Is this cost related?
 - How can ill patients at home get more medication, especially when feeling ill/vulnerable?
- Questions to patients being discharged need to be more in depth, such as “Who is there to help you? What is their contact number?”
- Mid Suffolk Axis – experienced patients being discharged without any knowledge that they are home (Axis). How does the hospital know the patient is getting help from Axis?
- Summary of care record – it would be great for this to follow the patient
- “This is me” life story – if used for every patient it would be brilliant. Same as patient passport across the board in Ipswich Hospital, people attach photo of family
- Patients are sometimes discharged with no medication
- Should start in primary care with the passport
 - Can community help with completion
 - Can it be done online?
 - Can it show medication changes?
 - Electronic passports available on line
 - Suffolk County Council
 - What is available already?
 - Action – look for patient passport online
 - Need to avoid duplication
- Lack of speech and language therapy for patients on discharge:
 - How is it picked up when patients go home?
 - Is there a community service?
 - Do people/clinicians know how to refer into service?
- All needs at home need to be in place before discharge
- For patients with no diagnosis there is not always a clear pathway and they regularly tip into crisis and go acute – how can their care be continued in the community?
- How do we find out about the patients we do not know about?



integrated working

- Is a health promotion person attached to GP surgeries? This person could contact people on discharge to ask if they are okay, do they need anything, do they need any advice/help? They need some knowledge of system and services available
- Do we need to 'tier' levels of support needed upon discharge?
- Does Age UK 'Welcome Home' link in with other voluntary groups involved in a patients care, such as Axis?

Parkinson's – Treatment and Services from diagnosis

- Needs to be more specialist Parkinson's nurses
- Neurology services do not sit well with other services – may have commonality with some dementia and mental health services, but it is a speciality in its own right
- All neurologist should signpost patients at the point of diagnosis to Parkinson's UK so that patients have access to up to date information and support when they feel able to access it and want the support
- Are self-management courses funded?
- West Suffolk has strong foundation of services but it must not sit on this – it needs to be build and develop these services. They need to be valued and essential to keeping people living well in community
- There is a mismatch between understanding and reality of the situation of people with the condition
- A good opportunity to development self-management model – work in partnership with other agencies (health, social care and voluntary sector)
- Education about right medication
 - Access to medication at prescribed time
 - Easier to manage at home, but very problematic in hospital setting, especially if Parkinson's is complex, and also if staff do not have information, understanding and education of its importance
- Smaller number of people may have Parkinson's than heart disease (for example), but costs of long term care will be greater if service provision does not meet needs at the appropriate times.
- Importance of information at all stages of the journey. Health professionals must signpost – it is what people with Parkinson's want
- Use Parkinson's UK as a resource and partner – it is there to help all affected by this condition

Age UK Suffolk

Human Resources both CCG's

Leisure services Bury St Edmunds, Sudbury, Hadleigh

Children's Centre 0-5 years

Awareness for health professionals in community services and signposting:

- Social isolation and physical activity
- Directory of services – where are these kept?
- Education days for GPs – voluntary services invited to, share their services to GPs
- More open door to surgery to help awareness.
- Organisations need help to access the right meetings with practice managers much more regularly
- Use resources to speak to surgeries to ask if there is a regular slot they have available that help awareness

How can all voluntary sectors engage more effectively with CCG?

Referral of patients into voluntary sector

- Suffolk congress
- Voluntary sector strategy



integrated working

- Trust the voluntary sector
- Should CCG map voluntary sector in Suffolk (in sectors)?
- Does the word 'voluntary' cause misperception of what can be achieved?
- Communication needs to be both ways
- Voluntary sector slot in practice newsletter
- Demonstrating voluntary sector values but get past this to achieve trust
- Information must be kept live and up to date for patients
- Strengthening links with patient reference groups – not all have GP representation

Patients Records

- One system
- Patient safety
- Access to own records on line
- IT systems (various)
- Patient knows best
- Yellow folders, such as those which hold end of life care plans
- 'You know my story'
- Summary care records
- Access 'permission levels'
- Health – system one/Egton medical information system
- Consent/Data sharing
- Patient experience
- Delivery of service
- Finance

Human-companion animal relationships

Many proven health and social benefits

Facilitate access to individuals, the isolated, and the physically and mentally frail

- Rapport built up
- Dignity team
- Separated – care
- Bereft
- Important to children
- Child development
- Go extra mile
- Our Special Friends
- More joined up working
- Community equipment service
- Need information/contact details to deliver (obstructive/barrier)
- Health records do not match with social care
- Data protection and some people can be a barrier
- Allow trust
- Tell same story once
- Allow sharing of details to voluntary groups and others
- Help support families
- Access other support so not expecting family member to cope
- Educating families re their responsibilities
- Ingrained behaviour
- Empower to break mould



integrated working

- Choice



integrated working

Families in Poverty

- How do they access the help they need to get the most appropriate help/care?
- Better partnerships between health and social care
 - Mental health worker sharing info with family support practitioners
 - Children's centres want more involvement with mental health, such as sharing information
 - Support health plans
- GPs and health centres need to direct/sign post people to children's centres
- Focal point (Health Watch beginning this)
- Families with housing issues are signposted to other services. However, there is a lack of joined up working, for example if snap involved case closed by social care (because snap involvement)
- Better for family for two services with health to continue working together to ensure long term good health and lifestyle
- Joined up working – housing left out of inclusion of health and social care
- Works well in children centre midwife clinics

What else can we do to support these people in poverty who do not, for example, breastfeed?

Q) Debt – how does the CCG support those in isolation?

A) Concept of local area coordination (being used) in the health and independence programme. It means people who are rooted in community can signpost/link people to the right place, and it can link older people with younger people. Benefits are less loneliness and mental health issues

Q) Challenge of the model – case worker

Can it sign off people as long term support is needed? Clarity of the role is needed. Is a helper long term support or short term? Can they do both?

Debt, poor housing, poor education, addiction all cause poverty and are a vicious cycle

The CCG can influence housing planning.

The CCG can influence assistive technology and disabled access

E-mail your GPs or have telephone access – this relies on patient ability to use e-mail or telephone for consultation

Costs of parking at WSH to have blood tests excludes poor people



integrated working

Dementia

- Early diagnosis and early referral are essential. Then people can go on to a specific consultant
- There are different types of dementia
- University of East Anglia:
 - Suffolk research
 - Prevalence low
 - Ipswich and east Suffolk – community based assessment /west Suffolk CCG – memory assessment
- Key worker
- GP input (with patient) engagement with carer who knows patient best
- Links to voluntary services
- Developing relationships with carers
- Primary care teams – there needs to be a broader understanding of patients' backgrounds and support mechanisms, such as carers
- Key worker approach
- Better information is available
- Dementia guide – use the Alzheimer's Society
- Good links to social care (change to home, etc)
- Health and social care (hands off)
- Joint budget
- Better Care Fund
- Self funding – no support/money
- Clarity on the support that patients can expect
- Carers in nursing homes
- Appropriate support
- Appropriate intervention – memory box/music
- Friends
- Knowing what works for the patient
- Knowing what the patient needs

Alzheimer Society

- Social Care – support early intervention
- Engage dementia friends, community and family
- Be a good neighbour
- Common sense – what is basic?
- Improve communications – use leaflets
- Isolated individuals
- Responsible carer
- Better communications to patient who has a lead/main carer
- West Suffolk Hospital and Ipswich Hospital should identify carers, perhaps through them having a passport
- Password – new initiative
- Need to access patient confidential information
- Links to shared care



integrated working

Coordination of dementia care services

- Single point of access
- Single conversation
- Seamless coordination at higher level
- Complexities re diagnosing dementia
- Information sharing is critical
- Social and health care are working together
- One overview – joint funded
- Similar gentle persuasive approaches models work in end of life care
- Keep vision simple
- More multicultural awareness needed

Information sharing for people with memory problems

- How do you get information on allergies for people with memory problems – not just dementia?
- Epilepsy causes memory problems
 - West Suffolk Hospital has an epilepsy specialist nurse and ‘advisor’ to offer information and support – more information on this service being available is needed
- Epilepsy Action has accredited volunteers able to give information – this includes memory problems and living with this
- Volunteers in Sudbury and Stowmarket – working across Suffolk
- Information needs to be comprehensively available on services for people
- Information should be held by people on them, their condition, treatment and how they live their lives with the effects
- Alzheimers Society
- ‘This is me’ campaign
- LiveWell – also good practice

Alzheimer’s

Concerned at lack of research in this area, and getting people to go to GPs for diagnosis



Identifying vulnerable individuals and providers umbrella support, advice, and key workers

- More holistic support is needed for others affected by repercussions of vulnerable individuals (there is often single parent support for individual and child)
- Prevention is better than cure
- What support is there? Lay out benefit entitlements to be able to understand what you're entitled to
- 'Joined Up' working is needed
- Key worker must be 'in the know' to coordinate services
- Comprehensive services lists needed for NHS and voluntary sector. People do not know what is out there
- Regular health checks (MOTs) needed for vulnerable people in hospital, but this gets lost and is lacking in the community
- Less phone use – more webcam as able to read facial expressions
- Locational issues can affect tele and Facetime conferencing
- Multi-disciplinary teams needed
- Credit card size information is ideal
- Vulnerable care worker/coordinator
- Awareness of vulnerable conditions
- What constitutes vulnerability? How is it identified?
- MS, epilepsy, mental health.
- Do not forget the 'invisible' vulnerable.
- Do not always force positivity – allow negativity
- Break down stigma
- If a specialist nurse coordinates care the holistic approach may get lost as they may give their special interest priority
- Manage vulnerable people to access what they need when it is needed. How will the care lead programme be evaluated?

How do we improve these (Patient Revolution) sessions?

- Need more patients here
- Why was it said that your attendance is 'up for approval'?
- Keep the formula, but we need to consider how we attract more patients
- Nothing about GPs
- Use market stalls to sign up people to these events
- Need more word of mouth
- Send direct letters to people who expressed an interest in attending
- Are we getting the hot issues here? Those that matter to patients
- Stress that you do not need any professional knowledge
- Spiral to a better place
 - ongoing issues
 - new issues as we progress
- Need to honestly build a conversation over the year about priorities
- Invite peers from other industries to attend to put their visions across
- Successful local businesses
- 'Doing it together'



integrated working

- Target through hospital mechanisms, such as appointments
- Think of targeting by theme, such as transport
- How to get more young people involved?
- Use YouTube to get views
- What are people saying on social media? Pick this up and then target them



integrated working

Improving dignity and respect

Care providers and social care

- Concern that joint working is not working effectively at ground level
- Need to improve dignity and respect and spread across all providers
- Need to further improve core values
- Ownership at every level of healthcare
- Taking time to listen to patients
- Suffolk 'going extra mile' awards last year encouraged organisations to promote what they excel at
- How is this fully communicated across local government and health?
- Are any services showing a particularly innovative approach?

Suffolk Community Healthcare

- Friend and family test
- Establish if patients are being treated fairly
- Into report – leadership team
- Gap analysis to then plan how could be improved
- Consider embarrassment
 - Sensitive question, such as commodes, require simple signposting
- Feedback – Healthwatch, CCG, patient experience group, staff groups, public forum
- Core values – putting person first, not just the task
- Clearly link to behaviours at every level of patient interface
- Organisations need consistency in approach to understand areas of concern
- Embed dignity and respect into every level
- Recruitment could be more focussed on core values and organisation 'fit' rather than just qualifications
- Could recruitment tools be enhanced?

Are there patient reporting mechanisms to understand dignity, respect, and inequality?

- How can we collate feedback in a fair way so that patients are not threatened?
- People feel comfortable reporting in an environment of personal care.
- Prejudice can be an issue, such as when dealing across language /patient environment
- Cultural differences
- Protection visible for whistle-blowers
 - More across providers
 - More understanding on disclosure and protection
 - Communications about this
- Pay and conditions:
 - Minimum wage
 - Retain good people
 - Personal skills to really relate to patient
- Need to make the most from the patient interface
- Do organisation Boards really 'walk the walk' on dignity and respect?
- People first –staff need to be treated with highest standards



integrated working

Transport

- Improvement needed to transport links from Haverhill to West Suffolk Hospital for appointments, and evening and weekend visiting
- Increase funding to surgeries where there are larger numbers of older patients than the national average
- Haverhill needs more out of hours doctors
- Increased access needed to West Suffolk Hospital transport
- Access to doctors on call needed in the future
- Extra money needed for GP practices which have a large number of elderly patients, who thus use the services more

Shared records:

- At the moment agree the notes should be shared, not just with consultant
- GPs advise ways of writing notes
- Sharing is only in the medical system
- Not exactly what you think it is going to be
- Worried about hidden agenda
- Fears about what is going to be shared
- More information needed about sharing of records

Physio:

- Is there a GP referral scheme in Bury for exercise? Abbeycroft Leisure
- Lots of people get results from physiotherapists and Stargo (SP). Some possibly need a gentle entry to exercise
- Link services to physical health
- There should be more information on GP referral to exercise
- People need to know about it



integrated working

Using the voluntary sector to support older people / Transporting Older People Support

- Good neighbour schemes
- Lunch clubs, social activities
- 'Food and Friends' cooking lunch for small group of local people in your home – can be simple, such as soup and bread
- Encourage young people to look after older people
- Use parish magazines to get volunteers
- Retaining volunteers is important – support and networking are valuable
- Fund volunteers for petrol costs and parking so they are not left out of pocket
- Going to hospital can be viewed as social event, so a district nurse visiting home rather than traveling to hospital may not be best option
- 'Chair' of good neighbours – can be formalised system
- Timing issues – neighbours may not be there
- Responsibility issues
- Commitment issues
- Volunteers need skills/training and back up from their organisations
- Fewer people want to volunteer these days
- Need to encourage more men to volunteer
- Ask people directly to volunteer – be pro active
- Street fair used to promote volunteering, such as in Long Melford
- Volunteering is a useful stepping stone to getting paid employment – get experience
- 'Link Visiting Scheme' – spend an hour with someone who cannot get out
- Telephone friends useful

Medication

- Compensation – responsibility issues and helping to manage meds
- Privacy issues
- Dossett boxes
- Training for volunteers to help with meds
- Husband/wife should help each other with meds rather than neighbours/volunteers
- Judgement issues would be needed to assess if patient has adequate or too many meds
- Get pharmacists to go to patients homes to check on the meds they have rather than expect voluntary organisations to do it
- Keep meds in a safe so only carer can control what is taken

Transport

- Helping with transport to hospital/medical appointments
- Volunteer drivers – 30/40 in village can be called upon for help in instances such as driving to shops
- Doctor may be close but referral appointments often far away, perhaps resulting in a £60 taxi fare
- Criteria for hospital transport must be met – friends and neighbours useful to help out



integrated working

Older People

Funding for GPs for taking on elderly patients

- Community hospitals for managing older patients
- Support GPs via integrated teams
- Review of funding distribution to account for older patients on a GP list
- Case for nurse practitioners to help with managing older patients
- Older population in Haverhill – high demand for health services and more likely to need hospital care.
- Issue of sustainability of smaller GP practices, such as Stourview in Haverhill

Chiropody – how does this fit into the CCG

- People get involved if it directly affects them and their needs at the time
- Chiropodists provide care for the feet and nails but often will not refer on associated orthopaedic issues
- In the Mildenhall area there is a long wait for chiropody services and irregular frequency between visits
- What is the difference between chiropody and podiatry?
- There is a lack of chiropodists
- Chiropodists can earn more money privately
- Seeking appeal redress if treatment refused
- It used to be the case that nurses could cut nails – this seems to have stopped because of worries over liability
- Foot care is essential to mobility and maintaining independence
- Consequences of poor provision are potentially grave for a lot of people
- Hip and knee replacements
 - Not allowed to bend beyond a certain degree
 - This can be a problem for foot care
- If you have arthritis, foot care is a major problem
- How can we improve the situation?
- How does the CCG provide chiropody?
- Does the CCG pay for this as part of a wider service?
- Good chiropody is essential to so many other aspects of healthcare
- Can a GP refer directly to a chiropodist?
- The service is not very joined up
- If you are on welfare benefits you can get it for free?
- Are the options for foot care clear for people?
- People would pay for a good service
- How does the referral work?
- Is this picked up during annual health checks?
- It is frustrating when clinicians do not ask wider questions about general health and wellness
- Feet are just as important as eyes and heart
- There should be an annual foot check
- Foot care is often seen by GPs as cosmetic
- Attitudes should change



integrated working

- It is about the impact on patients' lives



Managing community services with finite resources/accessing unmet need in community

- Do 'health' know about voluntary services are available?
- Needs to be clearer mapping of resources
- Ever evolving so hard to keep up to date
- 'My life' website – most up to date
- Frustration that funding of schemes is for such a limited period – it often ends once it is up and running
- Need earlier intervention to prevent people reaching crisis and needing longer term care
- There is a big issue with timing – need to prevent crisis point
- Multi-disciplinary teams at GP surgeries – a case of finding the most needy people but often not having enough time/ funding to do as much as it could
- Risk stratification (with intention of getting help to patients sooner) can help to identify patients , including voluntary services
- Health – good at 'identifying' patients but micro managing of people's needs might be best served by patients and their families
- There exists a mismatch between longer term identification and meeting people's needs now
- Need to manage people's expectations between what they would like and what is actually needed
- Funding of the voluntary sector is increasingly fundamental
- There are better ways of communicating, such as using the same IT system across teams
- Consistency across regular community is key as it enables patients to build a rapport with their carers
- Getting patient permission to share their care data can be challenging, such as aspiring to having a single care record
- Idea shared
 - Have a 'sign in' book for anyone being cared for at home, so all visitors write down who has been, the purpose of their visit, and can add questions for other visitors to answer
 - This really helps communication and highlights support/lack of support
 - It tracks when people have eaten, when care has been received
 - It keeps people and groups connected
- Multi-disciplinary team – step in right direction and done by each practice
- How do you get voluntary services involved in multi-disciplinary team
- A community outreach specialist? – they know the resources available in community and can get involved
 - Idea – posters for 'my life' in GP surgeries
 - More advertising needed
 - Plan to put it on Adult Community Services webpage
 - Can it be advertised on CCG/WSFT website?
 - Needs to be available in a printable format, so information can be printed off and shared



integrated working

Wasted medicine

Non compliance with medication

Over – use of repeat prescriptions

- 28 day prescribing is helpful
- Out Of Hours/Ambulance see patients bringing bags of medication to hospital
- Stockpiling of medication in case doctor changes to something the patient does not prefer
- Dementia may be cause of over ordering and stockpiling
- Hold drug amenities in car parks so it is not embarrassing to take to the community pharmacy
- More frequent medication reviews are needed
- Increased review should be done by surgery nurses
- Have the pharmacist as partner in practice to do the medication review from a strong link named pharmacist – GP practice
- Differences in medication reviews between dispensing and non-dispensing practices
- Poverty can cause stockpiling – for example, keeping half of antibiotics in case needed in future
- Parents order inhalers for their children so do not pay but use the inhalers themselves
- Drugs purchased on internet which are stockpiled can be dangerous
- Over ordering of dressings – some held back for use as surgery stock
- Nurses stockpiling dressings
- Feed back to GP when hospitals see patients coming in with bags of medication
- Smart medicines cabinet akin to a small fridge
- Improve quality of GP medication reviews