Neurology Strategy Forum

Thames Valley Strategic Clinical Networks

20 February 2015
Neurology Strategy Forum

Agenda

• Welcome, introductions and apologies
• Role of the Forum and Terms of Reference
• Thames Valley Update & Priorities
  • Buckinghamshire Stroke / Headache pathway priorities
  • Berkshire West Strategic intent
  • Berkshire East Parkinson pathway
• LTC QUIPP
• Mental Health in Neurology
• Patient Centered Care
• New models of care in Neurology
• Galvanizing change in Neurology
• Next Steps

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Neurology Strategy Forum

Objectives:

• Identify and agree local priorities for neurology for 2015/16
• Ensure alignment with national & local direction
  • five year forward view
  • local organisational objectives
• Agree way forward
  • steering group & terms of reference
  • work programme
  • engagement across TV
Buckinghamshire Stroke Pathway

Paramjit Singh
Chiltern CCG
20 February 2014
Context

- Approx half a million people
- Approx 550 strokes per year
- 52 GP practices
- Nearly the same area as Buckinghamshire County Council
- 2 CCGs – Chiltern in the south and Aylesbury Vale in the north
- A&E acute hospital in Aylesbury (Stoke Mandeville)
- Hyper-acute stroke unit (HASU) at Wycombe Hospital
- Nearby hospitals include Wexham Park (ASU), JR (HASU), Milton Keynes (ASU) and Luton and Dunstable (HASU)
Background

- Stroke network – running for some time past for interested stakeholders (image taken from an NHS file)
- Lacked governance and strategy
- Case of goodwill among clinicians and carers to improve stroke pathway
- Decision in May 2014 to reshape strategic planning and commissioning pathway
Evolution

- Right Care Steering Group (Planned Care programme board) took ownership for planning and governance
- Previous stroke network disbanded and incorporated into the Stroke Steering Group
- Aim to streamline pathway and drive whole system improvement
Governance

- **Stroke Care Steering Group** established May 2014
- TOR with clear governance arrangement
- Key stakeholder reps
  - BHT
  - ACHT
  - Social Services
  - Patient rep
  - Stroke Association
  - Public Health
  - Bucks CCGs
  - TV Stroke Network Clinical Director
- Clinical leadership provided by the Planned Care Clinical Commissioning Directors
Key Steps - first year

Year 1 - key actions agreed:

1. Review of stroke pathway – “Now and Here”
2. Build on early success of HASU
3. Use SSNAP to identify improvement opportunities
4. Develop work programme for 14/15 and beyond
5. Stakeholder workshop
Bucks Stroke Pathway

**CARDIAC & STROKE RECEIVING UNIT (CSRU)**
Wycombe Hospital

24 hour, 7 day service for patients staffed as a level 2 high dependency unit by specialist doctors and nursing staff; Total time in CSRU :< 4 hours

Patients who are undergoing thrombolysis treatment will remain in the CSRU until treatment is completed in the event that they need further imaging.

Patients not requiring thrombolysis will be transferred to the Hyper Acute Stroke Unit within four hours of arrival – HASU.
Bucks Stroke Pathway

Daily Transient Ischaemic Attack (TIA) Clinic 365 days/year

HASU
9 monitored beds and 3 escalation beds on ward 8 to provide hyper-acute care for first 72 hours

Identification of patients suitable for clot retrieval

Acute/Rehabilitation Ward 9; 26 beds on Ward 9 at Wycombe hospital

Discharge home, or to nursing home, or transfer to Bucks Neuro rehabilitation Unit (BNRU), Wexham Park, or John Radcliffe

Transfer patients to John Radcliffe Hospital for neurosurgical intervention

Buckinghamshire Neuro-Rehabilitation Unit (BNRU) Amersham Hospital
Following acute treatment until patient no longer needs the intensity of inpatient rehabilitation and is medically fit to be discharged from hospital;
Bucks Stroke Pathway

- **Aphasia/communication Rehabilitation and Support** provide intensive rehabilitation for communication difficulties post-stroke.

- **Early Supported Discharge (ESD)**
  Discharge from inpatient Stroke Services; 6 weeks post discharge.

- **Transfer of Care; Community Stroke Coordinator**
  (BHT for South Bucks)
  6 months post stroke; Bridge the gap between hospital and community settings.

- **Community Neuro-Rehabilitation Service (CNRS)** - Ongoing support after leaving hospital
  North team base: Rayners Hedge, Aylesbury
  South team base: Amersham Hospital (and Chalfonts & Gerrards Cross)

- **the Stroke Association** provides for North Bucks 0-6 months.
What did we learn from the review (1)

SSNAP headlines

Strengths

• Hyper acute management, including thrombolysis
• Stroke Unit care and rehabilitation
• Communication with families
• Patient health and social care plan
• ESD
What did we learn from the review (2)

SSNAP headlines

Strengths

- Post-discharge support via BHT and Stroke Association
- Community specialist therapy (CNRS and CHIS)
- TIA service
- Audit and Research
What did we learn from the review (3)

SSNAP headlines

Areas for improvement

- Speed of response to paramedics for advice
- Admission to HASU within 3-4 hours
- Nursing levels on SU (recruitment and retention)
- Rehabilitation ethos on the SU
What did we learn from the review (4)

SSNAP headlines
Areas for improvement

- Face-to-face therapy time (OT and SALT)?
- Efficiency of discharge planning
- Psychology input for acute stroke
- Use of patient portfolio
- Gap in service provision between ESD and CNRS/CHIS
Patient experience – ESD

Patient Satisfaction Survey
Q2 2014-2015

Survey Question

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Number of responses

- Very Satisfied
- Satisfied
- Dissatisfied
- Very Dissatisfied
Patient experience - ESD

Carers Satisfaction Survey
Q2 2014-2015

Survey Question

Qu1.
Qu2.
Qu3.
Qu4.
Qu5.

Number of responses

Very Satisfied
Satisfied
Dissatisfied
Very Dissatisfied
Thank You

Headache Pathway under review
Berkshire West CCGs
Neurology Strategy

Aasha Greensmith
Aasha.Greensmith@nhs.net
Overview

• Our Vision
• Why Neurology?
• Background to Strategy
• Creating our Strategy
• Strategic Objectives
• Priority Areas & Examples
• Consultation Period
• Next Steps…. 
Our Vision

- Our vision is that patients with neurological conditions will benefit from a transformed integrated neurology service spanning primary, secondary, tertiary and social care. Multi-disciplinary working will ensure patients are able to step up and down through the system when needed. Patients will feel empowered, with increased knowledge about their conditions and signposting to resources. Patients will feel less isolated and will be able to manage their condition better in the community.
Why Neurology?

- National recognition that neurology is not always recognised as an issue and the extent of problems are underestimated
- Local patient surveys/focus groups highlighting inequality of care and lack of co-ordinated care
- Concerns around high outpatient demand and activity
- Waiting lists for neuro-rehabilitation
Background to Strategy

• Joint Strategic Needs Assessment
  – Never formally signed off
• NHS reorganisation and CCGs established
• Long Term Conditions Programme Board established across Berkshire West CCGs
Background to Strategy

• Successes so far include:
  – GP neurological lead for each CCG
  – Joint appointment of Epilepsy nurse across Acute and Community Trusts
  – Headache pathway review
  – PDF grants for voluntary sector
  – Local recognition for work around neurological conditions
Creating our Strategy

• Lots of useful national strategies and papers available

• Needed to be relevant to local needs
  – Engagement with primary, secondary and community care
  – Engagement with the voluntary sector

• Enabled us to identify what is working well and where potential gaps are
  – Need to be able to identify work streams to take change forwards
Strategic Objectives

• Triage and Diagnosis
• Patient Empowerment
• Integrated Care
• High Quality Care
• Using Data and Information

Alignment with NHS England 5 year Forward View and Berkshire West Strategic Plan
| 1. Toolkits and training in Primary Care |
| 2. Appropriate access to specialist neurology staff |
| 3. Directory of Services, Signposting and other resources |
| 4. Care Planning with Patients |
| 5. Community Provision |
| 6. Use Of Technology |
| 7. Equal Access to Defined Pathways |
| 8. End of Life Care and Deterioration |
| 9. Access to neurology services and monitoring |
| 10. Meaningful communication with patients |
| 11. Prevention |
| 12. Integrated Health and Social Care |
| 13. Clinical Audit and Research |
| 14. Engage with Academic Health Networks |
| 15. Utilise local and national data |
Toolkits and Training in Primary Care

- Explore the use of training tools such as multimedia packages, flowcharts and decision support tools
  - Learn from evidence based practice
- Review of pathways to understand which referrals could have been managed in primary care
- Recognition this may be useful for clinicians other than GPs such as paramedics
Directory of Services, Signposting and Other Resources

• Directory of Services
  – Patient friendly version
• Increase awareness about voluntary services available
• Help patients become more well-informed, independent and confident in managing their conditions
• Ensure carers also benefit
Consultation

- External Consultation currently ongoing
- Will close on Friday 27th February
- March LTC Programme Board

- Learning points so far:
  - must ensure this strategy is inclusive enough and rarer conditions are represented as the strategy is implemented.
  - Greater recognition about use of pain services for neurology patients
Next Steps....

• Formation of the Working Group
  – Identify priorities and work streams

• Data Exercise
  – Benchmarking
  – Understand current pressure areas

• Pathway Mapping
Reviewing the pathway for Parkinson's

Dr Rishi Mannan – Clinical Lead– WAM CCG
Background

- Fragmented
  - Community services
  - Secondary/Tertiary care
  - Nurse Specialists

- System focused

- Active stakeholder and patient group
What we have done so far

• Developed working group –
  • Patients and carers
  • Specialists
  • Primary and secondary care partners
  • TVSN
  • Parkinsons UK

• Obtain data- scale of issue
The story from people living with Parkinson's and their Carers

- Surveys circulated through
  - the Newly Diagnosed Group
  - Slough, Windsor and Maidenhead Branch of Parkinsons UK
  - St Marks Community Clinic
- Responses from
  - 72 people living with Parkinson's, 6 of these newly diagnosed
  - 30 Carers
  - Age range from under 50 to 85+

‘The illness alone is very soul destroying for those with it and also their carers’
Key themes

• Overall care is
  • consistent
  • Professional
  • Patient centred
• But
  • Fragmented
  • Limited focus on education and self management
  • Limited availability of care plans
  • Timeliness of medication in hospital
  • Limited support for those being d/c from hospital
Do you know what a care/management plan is?

• 39% of people living with Parkinson's said yes
  • 37% of these people had one
• 15% felt healthcare professionals had access to the right information at point of contact

If there was one place where all of the information about you and your condition was kept, how would you feel? – 97% would feel positive
What we have done so far

- Developed working group – stakeholders including patients and carers
- Obtain data
- Mapped patient pathway
What we have done so far

- Developed working group – stakeholders including patients and carers
- Obtain data - scale of issue
- Mapped patient pathway
- Reviewed best practice
- Developed a patient focused pathway
  - Pre-diagnosis -> end of life
Draft Pathway - Management

- Chronic illness management
- Telemedicine
- Management
- Community Hub
- Parkinson's clinic
- Neurologist
- Gp
- Integrated care teams
- Parkinson's Nurse
- Clinician with special interest
- Community Mental Health
- Neuropsychology
- Community nursing
- Occupational Therapy
- Speech & language therapy
- Physiotherapy
- Care Plan
- Shareyourcare platform
- Education programme
- Self management
- Parkinson's UK/voluntary organisations
- Support groups
- Benefits/employment support
- Support groups
- Carer support

Build on existing developments

Holistic

Reduce travel burden
Draft Pathway - Exacerbations

Exacerbations -> Acute admission

Acute admission -> Protocols

Protocols -> Gp

Gp -> Early community discharge

Early community discharge -> Shareyourcare platform

Shareyourcare platform -> Out of Hours

Out of Hours -> Community teams

Community teams -> Integrated care teams

Integrated care teams -> Parkinson's team

Parkinson's team -> Admissions avoidance

Admissions avoidance -> Care Plan

Care Plan -> Telemedicine

Telemedicine -> Community Approach

Community Approach
What next?

• Engagement with Frimley Health Neurology
• Sign off of pathway by East Berkshire CCGs
• Develop service specification
  • Outcome measures
  • Timely accurate data
• Commission new service
URGeNT

Rachael Marsden
MND Care Centre Coordinator
Advanced Nurse Practitioner
Neurology Scoping Group

- Specialist Commissioning
- CCG
- OUH manager
- Clinicians
Two main aims......

• To Reduce Preventable Admissions
  QIPP Programme (Quality, Innovation, Productivity and Prevention)

• Emergency Care Plans
  CQUIN
  (commissioning for quality and innovation)
The two main aims....... 

Fortuitously match the same wishes that a group of us have been discussing for many years........
Admissions To the OUH

• For many reasons people with complex neurological conditions are best cared for in their own homes
• Many have a poor hospital experience*

* More data available
Pts. with a neurological condition

Have complex needs:

• Specialist carers who know their needs
• Need special equipment
• Many have problems communicating
• Problems mobilizing
• Take more nursing time

• All these issues require skilled knowledge and confidence to care
Preventable admissions to the OUH Jan 2014 -2015

**Falls** 38 patients  
504 bed days  
£151,000

**Urinary Tract Infections**  
125 pts. 1475 bed days  
£ 443,500

**Chest Infections**  
105 pts., 1114 bed days  
£334,200

**Total** – 268 pts. 3,093 days  
£ 927,700
Three unique problems with three unique solutions....
Suggestion to resolve this problem

URGeNT

- **U** = Urgent – not emergency but requiring immediate action
- **R** = Response – respond within a few hours
  8 am – 8 pm 7 days a week
- **Ge** = General  **N** = Neurology
  To include all pts. with a neurological condition: MND, MS, PD, PSP, Huntington, Muscular Dystrophy etc.
- **T** = Team – Physio’s with chest /neuro background
Our Aims……

• To prevent / reduce hospital admissions
• Most patients are known by a specialist neuro team
• Education of patients, carers & staff
• Use Emergency Care Plans to direct patients before a crisis occurs
Chest Infections

- Skilled Physio’s based in the West Wing.
- On call number
- Respond quickly
- Treat – cough assist, NIV, exercises etc.
- Liaise with GP
- Help to speed up discharge
Falls

• Currently not seen by Community Therapy Service because there is not an identified rehab goal- so are referred to PDPS and may wait for 16 weeks.

• Not seen by Falls Clinic as there is a known neurological condition
An extra neuro physio

- Exercise and education courses across the county for MS, PD and other neurology. The courses are planned to be 6 x 1.5 hour sessions incorporating an education element (falls, up from the floor, sitting to standing up, gait, mobility aids, benefits of exercise and where to continue to exercise) and an active exercise element.

- Improve the waiting time for patients at risk of falling

- Improve timely access to equipment – ability to run local clinics for mobility equipment
Urinary Tract Infections

Patient is given:

- Emergency care plan
- Education & information
- Home testing kit,
- Prophylactic antibiotics
The Way Forward

• a Pilot Study to be able to demonstrate just how effective these suggestions could be in helping to reduce preventable hospital admissions.

• Audit findings
URGeNT Group

- Julie Young – Senior Physio Sleep Team
- Nuala Reeves – MS Advanced Nurse Practitioner
- Jo Bromley / Sue Barnden – Community Neuro Nurses
- Simon Lovett – Senior Physio Neuro Ward
- Jane Freebody – Specialist Physio Muscle Disease
- Alice Fuller – Campaigns manager MNDA
- Mark Stone – Patient Representative
- Lesley Hoare – Senior Physio Community
- Clare Sander – Patient Representative
- Karen Pearce – MNDA Director of Care - South
- Kathy Hymas – RCDA MNDA
Thank you

Rachael.marsden@ouh.nhs.uk
Pager 07659 112481
Mental Health in Neurology: Current and Future Need

Dr David Okai MD(Res) MRCPsych MB.BS. B.Med.Sci. CBTDip

Locum Consultant Psychological Medicine: Oxford
Clinical Research Associate in Neuropsychiatry: Institute of Psychiatry
Service provision in the 21st century

- Gradual rapprochement of Neurology and Psychiatry
- Marked divisions still apparent in service planning
- Increasing calls to integrate neurological practice and training with psychiatry

(Eisenberg, 2002; Mitchell & Agrawal, 2005)
NHS Outcome Frameworks

• National Service Framework
  – Need for early identification of cognitive, behavioural and mood symptoms in neurological patients
    (DoH, 2005)

• Parity of Esteem
  – Enhancing quality of life for people with LTC
  – Ensuring that people have a positive experience of care
    (RCPsych, 2013)
Existing service provision

• Relatively few specialist regional centres provide input throughout the UK

• Geographic distance has been found to be associated with unmet need

(Fleminger, 2006)
RCPsych: Neuropsychiatry special interest group

• Section of Neuropsychiatry
  – NHS consultants
  – Academics
  – Private sector

  – 70 consultants with some involvement
  – 21 primarily employed as neuropsychiatrists
## Neuropsychiatry services provided by the respondents *

<table>
<thead>
<tr>
<th>Types of Services</th>
<th>n (%)</th>
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<tbody>
<tr>
<td>Out-patient service</td>
<td>19 (90.5)</td>
</tr>
<tr>
<td>Specialist neuropsychiatry service</td>
<td>18 (85.7)</td>
</tr>
<tr>
<td>In-patient beds</td>
<td>13 (61.9)</td>
</tr>
<tr>
<td>Neuroscience liaison psychiatry</td>
<td>13 (61.9)</td>
</tr>
<tr>
<td>Special interest clinic</td>
<td>12 (57.1)</td>
</tr>
<tr>
<td>General hospital liaison psychiatry</td>
<td>10 (47.6)</td>
</tr>
<tr>
<td>Day patients</td>
<td>7 (33.3)</td>
</tr>
<tr>
<td>Community Nursing</td>
<td>5 (23.8)</td>
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</tbody>
</table>

*Doctors were providing more than one service

(Neuropsychiatry Special Interest Group, 2008)
<table>
<thead>
<tr>
<th>Types of Conditions</th>
<th>n (%)</th>
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</thead>
<tbody>
<tr>
<td>Brain Injury</td>
<td>20 (95.2)</td>
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<tr>
<td>Epilepsy</td>
<td>19 (90.5)</td>
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<tr>
<td>Cognitive and memory disorder</td>
<td>17 (81.0)</td>
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<tr>
<td>Liaison psychiatry</td>
<td>15 (71.4)</td>
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<tr>
<td>Neuropsychiatry of developmental disorder</td>
<td>15 (71.4)</td>
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<tr>
<td>Neurological unexplained symptoms</td>
<td>13 (61.9)</td>
</tr>
<tr>
<td>Movement Disorder</td>
<td>13 (61.9)</td>
</tr>
<tr>
<td>Sleep disorders</td>
<td>12 (57.1)</td>
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<tr>
<td>Other</td>
<td>3 (14.3)</td>
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</tbody>
</table>

(Neuropsychiatry Special Interest Group, 2008)
Funding

- Local Primary Care Trust: 40%
- Mental Health Trust: 20%
- Out of area SLA: 17%
- General Hospital Trust: 8%
- Neuroscience Centre: 5%
- Strategic Authorities: 5%
- Other: 5%
<table>
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<tr>
<th>Referral Pathways</th>
<th>n (%)</th>
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<td>Source of referrals</td>
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<tr>
<td>Psychiatrists</td>
<td>19 (90.5)</td>
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<tr>
<td>Neuroscience clinicians</td>
<td>18 (85.7)</td>
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<tr>
<td>Other general hospital consultants</td>
<td>17 (81.0)</td>
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<tr>
<td>General practitioners</td>
<td>16 (76.2)</td>
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<tr>
<td>Specialist Units</td>
<td>12 (57.1)</td>
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</table>

(Neuropsychiatry Special Interest Group, 2008)
Service model and team composition: considerations

• One size does not fit all!!
  – Clinical demand
  – Configuration of neuroscience services
Outpatient neuropsychiatry - considerations

- Outreach
- Referral rate 20-30 per 100,000
- 666,000 Oxfordshire population
Inpatient neuropsychiatry

• ? need for beds
• Review of those who attend neuroscience unit
• Day-patient facilities
• Challenging behaviour
Commissioning

• Organisational issues
• Lack of clarity roles and responsibilities
• Variable funding sources

• Need for joint business planning
  – Close working relationship needed between mental health, neuroscience providers and commissioners.
Pilot – Imperial College London

1) **Inspire collaboration** and integration of services

2) **Decrease emergency admissions** by 30% and nursing **home admissions** by 10% for diabetics and frail elderly

3) To overall **reduce cost** of these groups by 24% over 5 years

4) Significantly **improve patient experience**

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**Three core benefits:**

- Improvement to quality of patient care
- Creation of a richer professional experience
- Improved Finances

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**Pilot – Imperial College London**
Pilot – Imperial College (2)

Clinicians will develop a more pro-active approach to managing care through more frequent interaction…

Group (50,000+)
Sub-Group (~10,000-30,000)
Summary

• Increasing stream of neuropsychiatrists
• Mainly based in regional centres
• Slow but progressive expansion of services
• Lagging behind integration process in others areas (E.g. Cancer, Perinatal, Renal, Child services)
• Need for greater collaboration in the establishment of services
The House of Care Model

Sylvie Thorn
Service Development Manager for Long-Term Conditions
The House of Care Model

- A model for long-term conditions
- Developed by the Year of Care partnership
- Based on international evidence and best practice experience in the UK
- Piloted extensively
Long term conditions are different

Hours with healthcare professional
= 4 hours in a year

Self-management
= 8756 hours in a year
Traditional practice styles aren’t working

- Create dependency
- Discourage self-management
- Ignore personal preferences and resources
- Undermine confidence
- Do not encourage healthy behaviours
- Increase fragmentation of care
The evidence base in all long term conditions

Engaged empowered patient

Organised proactive system

Partnership = Better outcomes

In England: The Diabetes NSF

Internationally: The Chronic Care Model - Wagner
Organisational processes

Engaged, informed patient

Collaborative care planning consultation

Commissioning - The foundation

HCP committed to partnership working
Personalised Care Planning

• It is a meeting of equals.
• A partnership of expertise
It about the quality of the conversation
Rather than the care plan template....

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<th>Need</th>
<th>Objective</th>
<th>Action Plan</th>
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<td>Address mental health issues</td>
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<td>Address physical health issues</td>
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<td>Address offence related therapeutic issues</td>
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<td>Address relationship issues</td>
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<td>Address occupational and recreational issues</td>
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<td>Address self care issues</td>
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<td>Assess self control and acceptance of personal responsibility</td>
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<tr>
<td>Address other risk management issues</td>
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<tr>
<td>Develop future plans</td>
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Colum 5 : N – New, D– Discontinued, C – Continued (With change), O – Ongoing (No changes)
Personalised Care Planning

- Individuals’ values and concerns shape the way in which they are supported
- People are prepared and informed
- Builds on individuals’ strengths and resources
- Requires the HCP to think in a different way
- Requires the development of HCP skills and knowledge to facilitate the conversation
What is means to individuals with LTCs

• Motivates people
• People are prepared and informed
• Improved confidence to manage their own health and healthcare.
• Recognises their assets, strengths and abilities, not just their needs.
• Solutions designed and delivered with people rather than 'to' or 'for' them
• Individuals’ values and concerns shape the way in which they are supported
“I can plan my care with people who work together to understand me, allow me control and bring together services to achieve the outcomes important to me.”
Improving Individuals Experience and Behaviour

‘I feel more in charge both during the consultations and in managing my condition’

‘I achieve a lot – I have become very conscious of what I eat and do more exercise. I started going to the gym to lose weight’

‘Each time I get a greater understanding of my condition and understand more about how I can go about maintaining and improving it’.
Improving Staff Satisfaction & Effectiveness

‘I enjoy doing the clinic a lot more now... working with them rather than at them’

‘We have used the YoC as a template for other care packages.’

Care planning has made me look at patients differently. .... I have to invest more time .... but it will get easier ....as people get more used to it.’

‘It’s absolutely 100% better for me and for the patients’
Benefits to the system

- Greater adherence to treatment regimes
- Reduction in acute and emergency healthcare use by anticipating and making provision for possible crises
- More likely to use less costly healthcare
Reduction in demand for healthcare

- Small shifts in self-care impact on demand for professional care:
  - 5% increase in self-care → 25% reduction in demand
  - 10% reduction in self-care → 50% increase in demand

Sobel 2003, cited in *Time to Think Differently*, King’s Fund 2013
Training available in Thames Valley

Thames Valley Strategic Clinical Network -

- Provision of a rolling programme of education and training for health professionals
- Establishment of experts available for advice and support for implementation
- For further information Julia.coles1@nhs.net
Lessons from psychiatry

True Colours

John Geddes

National Institute for Health Research
Limitations of anamnesis

- Prominent role in medical practice
- Reliance of retrospective/cross-sectional data
- Major problem in psychiatry – but recognised by colleagues across medicine
Management of chronic illness

• Hard to target care
  – Right time
  – Right person
  – Right place
What is True Colours?

• Self-monitoring and management system for long-term health conditions

• Texts, email, online

• Graphs to track symptoms, accessed by client and clinician
  – Notes
  – Uploaded to Rio
Benefits of True Colours

**Patients**
- Self-manage
- Understand symptoms
- Identify relapse signals
- Share graphs with others

**Clinicians**
- Symptoms reported accurately
- Relapse prevention plans
- Guides self-management
Questionnaires

QIDS
• Depression
• 16 items

Altman
• Mania
• 5 items
and more questionnaires...

**EQ – 5D**
- Quality of life
- 5 items

**PHQ - 9**
- Depression
- 9 items

**GAD - 7**
- Quality of life
- 5 items
SEARCH

Type in some details to find a patient.

Last Name:  
First Name:  
NHS Number:

Level of confidentiality required:
- Specific patient only (maintains other’s confidentiality when patient present)
- List all patients meeting search criteria (not safe in the presence of patients)

More Fields...
Clear Fields

Download Caseload PDF

+ NEW PARTICIPANT

SEARCH
<table>
<thead>
<tr>
<th>First Name</th>
<th>Last Name</th>
<th>TC Number</th>
<th>NHS Number</th>
<th>Days Since Last Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Albert</td>
<td>Einstein</td>
<td>1</td>
<td>68926554</td>
<td>10 weeks, 6 days</td>
</tr>
<tr>
<td>Alessandro</td>
<td>Guazzi</td>
<td>10120</td>
<td></td>
<td>34 weeks, 6 days</td>
</tr>
<tr>
<td>Alessandro</td>
<td>Volta</td>
<td>39</td>
<td>20226185</td>
<td></td>
</tr>
<tr>
<td>Alexander</td>
<td>Bell</td>
<td>22</td>
<td>33788501</td>
<td></td>
</tr>
<tr>
<td>Alfred</td>
<td>Nobel</td>
<td>27</td>
<td>56736187</td>
<td></td>
</tr>
<tr>
<td>Amedeo</td>
<td>Avagadro</td>
<td>36</td>
<td>93353391</td>
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</tr>
<tr>
<td>Antoine</td>
<td>Lavoisier</td>
<td>40</td>
<td>34318065</td>
<td></td>
</tr>
<tr>
<td>Ash</td>
<td>Wadekar</td>
<td>10199</td>
<td>99999999956</td>
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</tr>
<tr>
<td>Ash</td>
<td>Wadekar</td>
<td>10201</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Evaluation

• Routine data
• Randomised trials
• Health economics
• Qualitative
**Benefits of using True Colours:**

<table>
<thead>
<tr>
<th>Patient benefits:</th>
<th>Clinician benefits:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Learn self-management skills</td>
<td>• Provides a structure for guiding self-management of symptoms</td>
</tr>
<tr>
<td>• Gain a better understanding about what influences symptoms</td>
<td>• Provides an accurate picture of symptoms since previous appointment which can inform treatment plan</td>
</tr>
<tr>
<td>• Learn how to use True Colours to identify early signs of relapse</td>
<td>• Helps to create individual relapse prevention plans</td>
</tr>
<tr>
<td>• Can share graphs with friends and family who have a supporting role</td>
<td>• Enables remote monitoring of symptoms so that contacts can be linked to times of greatest need</td>
</tr>
</tbody>
</table>
What do patients think?

“It’s brilliant….it is difficult to remember when I’m at the clinic how I felt weeks ago, whereas SMS captures it.

…it’s nice to feel that even when I’m not seeing the doctor it’s being charted…it quantifies how I’m feeling…helps make clinical decisions.”

“[daily monitoring was] quite an eye opener … when you look at how much you do and don’t sleep. Because I just forget from day to day and how much that affects you the next day. To see it in hard copy rather than just going round in my brain….. I found it really helpful.”
Further development

• App – iOS and Android
• Other data streams – HR, activity, sleep, ECG, EEG etc etc
• Linked devices
• Reverse translation from phenotype to biology

CONBRIOT

Wellcome Trust
Neurology Strategy Forum

Discussions

• 4 groups
• Discuss and agree the “what and the how” of the proposed pieces of work
• 15 minutes discussion in each group
• 5 minutes each group to feedback
• Flip chart for other ideas
Neurology Strategy Forum

What and how?

Group 1
• Moving towards patient centred care

Group 2
• Embedding informatics into patient care systems

Group 3
• Reducing admissions for LTC

Group 4
• Develop and deliver integrated pathways