

DRN Patient Involvement Conference, 4th December 2008 - Amalgamated Feedback from World Café Event discussions

Workshop 1

“What can we do to make research more accessible?”

Raising awareness of diabetes and research

- Put it into soap operas!
- More newspaper headlines. More hard-hitting headlines: “Are you sure you haven’t got it?”
- Advertise in media, in user support groups – advertise more widely
- Advertise patient involvement more widely – make universities more aware of it
- Target the difficult to reach groups
- Produce simple leaflet about diabetes research – need to promote it
- Start with GPs and hospitals, to reach the newly-diagnosed - leaflets and posters in GP practices, diabetes clinics, pharmacies, relevant clubs, etc.
- Leaflets in plain English – for diabetes specialist nurses to distribute
- Information packs on research for newly-diagnosed
- Get out to communities – give information out, don’t leave it lying around!
- Not everyone likes groups – need to get to ‘individuals’
- Range of ways of reaching people
- Take research out to schools – raise awareness among next generation (MCRN already doing this)
- Promotional events – blood testing in shopping centres etc
- DRN to give talks to community groups, organisations – lay and professionals to do this
- Set up patient forums in different areas – split up the networks
- Need to motivate the public
- DRN to organise events – walks, fun days, chance to explain what research involves

Making research more accessible

- ‘Information’ about research needs to be accessible to make ‘research’ accessible
- Make findings more easily available
- Too much/too little information can be dangerous
- Make research more convenient – where do people go to find research?
- Make language more accessible – plain English please – jargon-busting!
- Make research more understandable, offer comprehensive information
- Local support groups to “adopt a project” through Diabetes UK to gain understanding of research projects – Diabetes UK lists projects they have funded
- More detailed information on research studies in ‘Balance’
- Ensure “failed” research is published, not just the “the good”
- Better communication methods
- Offer compensation for taking part in research
- Diabetes UK/DRN to provide regular updates as to what is going on to local support groups
- In South West, ‘PCs for GPs’ project – searchable for patients and staff
- Make research part of the culture

Improving knowledge and training

- Better GP and nurse training on research – look at culture of healthcare professional training
- More funding towards research nurse training
- ‘Quality Outcomes Framework’ points for GPs taking part in research
- ‘Diabetes Digest’ – research and development – applying research to something or somebody
- Patient Audits – to see how they are, and to offer advice
- Break down prejudices – works both ways. For patients, ‘what is research?’ and ‘why would anyone listen to me?’ For doctors, ‘doctor knows best?’

Workshop 2

“What would you like to see diabetes research deliver in the next 20 years?”

Care and treatment

- A cure! A cure for type 1 – type 2 more difficult.
- Better understanding of the causes
- Treatment-targeted therapies – genetics
- More research into better medicines for diabetes
- Long-lasting implants for type 2 – e.g. 3 months
- Elimination of hypos
- Insulin infusion without injections
- Research into diet and dietary advice
- Research into exercise programmes similar to those offered to overweight and cardiovascular patients
- More research into prevention of heart disease linked to diabetes
- More general testing for cholesterol, etc
- More research into why people can't achieve targets – e.g. HbA1c – and what they can do to help achieve these targets
- Research into psychological impact of living with diabetes
- More positive psychological advice – “how to live with diabetes”, not “a life sentence”
- Advice on involving partners and family members in psychological aspects of diabetes
- More quality of life research – more qualitative research generally
- More genetic research. Why is it that some people have complications whilst others can live with diabetes for many years without any complications?
- More research into pump technology – make them more accessible and useable for a wider range of people with diabetes.
- Pumps for those who want them, not having to “fight for treatment”
- Pumps to be replaced by artificial, mechanical pancreas – or the iPancreas
- Research into differences in care between secondary and GP practices
- Models for delivery of care in communities
- Community-based diabetes clinics – more drop-in centres to give support
- How many PCTs have special budget for diabetes?

Diagnosis

- Better methods of diagnosis – more specific diagnosis
- Routine screening for diabetes – a National Screening Programme to detect diabetes early
- Research into the psychological impact of diagnosis, how and why people react to their diagnosis differently
- Pre-natal screening for mother and baby
- Regular testing for early detection of diabetes – genetic testing for prevention
- Regular testing for diabetes when associated conditions diagnosed – polycystic ovary syndrome, etc

Prevention

- A good understanding of the causes of diabetes (e.g. environmental)
- More research into prevention of diabetes
- Genetic profiling to identify inherited individuals early

Monitoring

- End to skin-prick, invasive testing
- Different ways of measuring blood glucose levels – better devices making it easier to measure in public places.
- ‘Diabetes Watch’, alerting wearer when necessary
- Reliable blood glucose measuring – not taking an average of several measurements
- HbA1c checks to take place in GP surgeries – e.g. auto-analyser

Support

- Starter packs for the newly-diagnosed to combat information overload – make it personalised, less depressing, how to live with diabetes (not how to die from it)
- 24-hour national helpline – e.g. for pump failure on bank holidays – stop having to buy a second in case of breakdowns
- National back-up for pumps – not postcode lottery

Culture changes

- Make people aware that diabetes is nothing to be afraid of – people need awareness and the correct information
- Make it more acceptable to have diabetes – no more scaremongering, make diabetes less frightening

Education

- Starter packs for the newly-diagnosed – to combat information overload (how to live with diabetes)
- Better awareness of complications
- Better education programmes for patients – and qualitative research into them to find out what works!
- Education programmes that are cost effective and accessible, and easy to deliver – DAFNE and DESMOND too costly
- Better education for kids
- Better knowledge about infections
- Better education about involvement – more involvement at Diabetes UK

Healthcare Professional Training

- Better education for healthcare professionals, especially in GP practices, providing wider knowledge of condition among healthcare professionals
- Fully-informed healthcare professionals – often treated as ‘acute’ condition, not chronic disease
- Better diabetes knowledge as part of general nurse training
- Better knowledge for non-diabetes specialists, as often admitted with other health problem
- Improving healthcare professionals’ delivery of essential information

Research process

- Better access to research outcomes
- A survey on un-asked questions: What would you like to see? Will there ever be a cure?
- More patient say in the funding process
- More lay-led research to be supported

Awareness

- Raising awareness at Government levels that ‘increasing numbers means increasing cost’ – so more money needs to go into diabetes research
- Government to understand short-term funding can lead to long-term gains
- Government encouraged to financially support those on insulin pumps
- Annual, authoritative statement on diet and dietary advice – lots of conflicting advice now
- Government to bring pressure on food manufacturers to restrict sugar, salt and fat in foods

Workshop 3

“What support would you like to help your involvement in research?”

Training

- Training is very useful, although must be appropriate and relevant – otherwise may be danger of becoming “professional” – a balance is needed
- In-depth, knowledge-based training
- Training about research process – including terminology, funding and finances, etc
- What makes a good research study?
- Training for presenting skills
- Training for critical analysis – existing course in Hatfield good
- Assertiveness training
- Communications training
- Confidence-building – to combat intimidating medical world
- Professional trainers – how to put your view forward, when to step back
- More funding for training
- Use of on-line tutorials and group tutorials
- Accreditation for training would be beneficial
- Include non-diabetics in education programmes to broaden knowledge
- General diabetes education – and awareness of complications
- Deliver in different ways – not just groups
- “Make training a positive experience!”

Financial

- Upfront payment of expenses – avoid delay in repayment
- Payment – majority say no, as long as expenses paid (North East London pay)
- Attendees should not have to ask if financial support is available for attending meetings, etc. This should be made clear from the outset to remove any worry about the financial burden of becoming involved
- Knowledge of what expenses/payments you are entitled to
- Advice and awareness of benefits and tax issues and implications

Information and events

- Better information about involvement – for researchers as well as public
- Clearer information about what meetings entail
- More notice about events/meetings – more planning and preparation time means better involvement
- Voices to be heard and respected
- Regular updates
- Share good practice across the DRN
- More regional events
- Events more like this, to share experiences
- “Today’s meeting has been tremendous, can we have another?”
- Information on what types of studies there are
- Feedback on patient/carer contributions and impact, particularly at the start – whether objectives set as a result of suggestions, what has changed?

General support

- Help in setting up local support groups
- ‘Balance’ magazine to change – get rid of recipes, more research articles
- Peer support – meeting and discussing issues helps to put things into perspective