Macleod House
10 Parkway
London NW1 7AA
England

European Commission
Health and Consumer Protection Directorate – General
Health Services Consultation
B232 8/102
B-1049 Brussels
Belgium

30th January 2007

Dear Sir/ Madam,

Please find enclosed the response from Diabetes UK for the European Commission consultation on Community Action on Health Services.

Diabetes UK is one of Europe's largest patient organisations. Our mission is to improve the lives of people with diabetes and to work towards a future without diabetes through care, research and campaigning. With a membership of over 175,000, including over 6,000 health care professionals, Diabetes UK is an active and representative voice of people living with diabetes in the UK.

Facts about diabetes

- Prevalence of diabetes is 2.2 million in the UK. It is predicted that diabetes prevalence will double world-wide, accounting for 3.07 million people in the UK.[i]
- Diabetes affects the young and old, and has particularly poor outcomes in those of lower socio-economic status and in those from black and minority ethnic groups.[ii,iii]
- Evidence is available supporting the need for improved education of people with diabetes and their carers if better control and improved outcomes are to be achieved.[iv,v,vi]
- Diabetes, if undetected or not well managed, can lead to many complications and have a devastating impact on quality of life.

Diabetes UK is responding to this consultation in the context of:

- People with diabetes living in the UK who may go to other EU Member States in order to receive parts of their healthcare
- Healthcare professionals from other EU Members States coming to the UK to provide healthcare
- Remote healthcare provision
- Healthcare provider organisations from other EU Member States providing services in the UK.

In summary Diabetes UK sees the key issues to be addressed as:

- Good quality information about a patient's rights, entitlements, and the potential benefits, risks and implications of receiving cross-border healthcare should be made available to patients to inform any decision they choose to make. A system to enable the comparison of Europe wide clinical standards and practice would support practitioners and patients to have some level of assurance.
- Consideration needs to be given to how the delivery of care in another Member State will impact on follow up for the patient in their home State, particularly if unfamiliar technology / medication is used in the other Member State. Systems of communication are crucial to ensure the continuity of care for that patient.
- Lines of accountability must be clear to protect patients and will vary according to who has authorised or informed patients about a particular provider. The Member State providing the care should be responsible for regulating the care provided.
- Systems to support the sharing of international evidenced based practice are essential.
- Europe-wide standards for diabetes care delivery are needed so that people with diabetes in all Member States can be guaranteed to receive the same standard of high quality care and treatment. An EU Recommendation on Diabetes could indicate a minimum standard for all EU member states to follow. The UN resolution on diabetes highlights the need for governments world wide to have policies in place to improve diabetes care provision.

1. **What is the current impact (local, regional, national) of cross-border healthcare on accessibility, quality and financial sustainability of healthcare systems, and how might this evolve?**

   In diabetes care, services are planned, commissioned and provided locally in partnership with people with diabetes, clinicians and other stakeholders. Capacity is based on a local needs assessment using available data about the locality. This work locally is underpinned by national clinical guidelines and standards set out in National Frameworks/ Guidelines[7,8,9,10]. People with diabetes receive ongoing care and support from the NHS, who use the clinical guidelines, developed by bodies such as NICE in England. Ongoing care includes information and structured education to enable a person with diabetes to effectively self - manage their condition. Access to local, regional, and national UK services is gained via GP referral, with GPs acting as a gate keeper to the rest of the system. People will normally be seen by different healthcare professionals 6 monthly to annually during the course of their lives for routine tests and will receive additional support

to inform their self management. If a person develops complications such as retinopathy, cardiovascular disease or nephropathy then they may require specialist help from acute services. People with diabetes might seek treatment for a complication from another Member State if they believe this will be of benefit to them under their circumstances.

We are currently not aware of examples of people with diabetes who are receiving cross border care for their ongoing care needs. However it is likely that some people will have the means and cause to access care for specific complex procedures.

Underpinning all of this consultation is the need to clarify the legal and practical rights and entitlements of people with diabetes who choose to live in more than one Member State as their ongoing care needs may be catered for across more than one Member State. Clarification is needed as to which Member State's health system they are considered as belonging to.

2. **What specific legal clarification and what practical information is required by whom (e.g. authorities, purchasers, providers, patients) to enable safe, high-quality and efficient cross-border healthcare?**

- It is paramount that patients are given information about their rights, entitlements and what the potential benefits, risks or implications of receiving treatment in another Member State may be. Patients and providers in the patient's home State will need to have good quality, reliable information about the service/ treatment they will be provided with so that they can make informed choices. A system to enable the comparison of clinical standards and clinical practice would help patients and providers to weigh up the costs and benefits of choosing treatment in another Member State and could also act as a measure of assurance of the quality of care to be received.
- Differences in the technology or medication used may also have implications for a patient with a long term condition in terms of the follow up when they return to their home State. They will need to be made aware of these potential implications. Systems of communication are also crucial to ensure the continuity of care for a patient and ensure joined up working in line with a patient's care plan[12].
- Further to this, patients will need information about costs and whether the NHS will be able to pay fully for the patient's treatment in another Member State.
- Patients will also need to give informed consent for the release of their health details so that they can be safely cared for in another Member State, for instance using the European Health Insurance Card.
- Time frames for the authorisation of consent for care to be paid for by the home State to be delivered in another Member State should be based on an individual's specialist's recommendations on a case by case basis, to avoid undue delay.

3. **Which issues (e.g.: clinical oversight, financial responsibility) should be the responsibility of the authorities of which country? Are these different for the different kinds of cross-border healthcare described in section 2.2 above?**

Any provider or practitioner of healthcare within a given Member State should meet that particular State's clinical practice requirements and be regulated and quality assured according to that State's requirements. In the case of telemedicine, the accountable local healthcare organisation in the receiving State will need to ensure they are satisfied of the standards of provision although without a common regulatory framework it will be difficult to monitor this provision on an ongoing basis.
Financial responsibility should lie with the Member State that has failed the patient.

4. **Who should be responsible for ensuring safety in the case of cross-border healthcare? If patients suffer harm, how should redress for patients be ensured?**

Clear lines of accountability must be in place to protect patients. Where a Trust / Board is giving authorisation for a patient to receive healthcare, either in or from a provider within another Member State then that Trust/Board should be responsible for ensuring that the provider is fit for purpose. When a Trust/ Board does not need to give authorisation, and a patient opts to undertake cross border care privately then mechanisms are needed to ensure systems of redress are available under these circumstances and will require investigation into how this would operate within different Member States' health systems. In order to protect patients who opt for cross-border treatment of their own volition a system needs to be put in place for their protection, where they can seek redress from the State where they have suffered harm. Consideration should be given as to how patients can seek redress as they may not be financially able to undertake this themselves

Although the internet is notoriously difficult to regulate, the development of some form of recognised, Europe-wide, quality assurance mechanism, where assured providers are registered on a European database would enable individual patients and practitioners to have some quality assurance available to them. This system should be promoted publicly in Member States as part of public information about cross-border healthcare.

The Member State providing the care and treatment should regulate this provision, and healthcare professionals/ providers working in a different Member State are to be regulated as fit to practice by the country they are working in, and should be working towards that country's clinical and care standards.

5. **What action is needed to ensure that treating patients from other Member States is compatible with the provision of a balanced medical and hospital services accessible to all (for example, by means of financial compensation for their treatment in "receiving" countries)**

Benchmarking of diabetes care and treatment across all Member States is needed to inform patients, practitioners, and individual Member States of their referral choices.

8. **In what ways should European action help support the health systems of the Member States and the different actors within them? Are there areas not identified above?**

Systems to support the sharing of international evidence based practice are essential to support access to consistent standards of care. Europe-wide standards for diabetes care delivery are needed so that people with diabetes in all Member States can be guaranteed to receive the same standard of high quality care and treatment, whilst recognising that the care pathways in the various Member States will be different. The UN resolution on diabetes highlights the need for governments world wide to have policies in place to improve diabetes care provision.

Diabetes UK contact

Stella Valerkou
Good Practice Co-ordinator
Macleod House
10 Parkway
London NW1 7AA
England
stella.valerkou@diabetes.org.uk

Yours faithfully

Stella Valerkou

Diabetes UK

---

[i] Amos AF, McCarty DJ, Zimmet P. The Rising Global Burden of Diabetes and its Complications: Estimates and Projections to the Year 2010. Diabetic Medicine. 5: Volume 14. 1997

[ii] Chaturverdi N, Jarret J, Shipley MJ, Fuller JH. Socio-economic gradient in morbidity and mortality in people with diabetes: Cohort study findings from the Whitehall Study and the WHO multinational study of vascular disease in diabetes.BMJ 1998; 316:100-106

[iii] Mather HM, Chaturverdi N, Fuller JH. Mortality and morbidity from diabetes in South Asians and Europeans: 11 year follow-up of the Southall Diabetes Survey, London, UK. Diabetic Medicine 15: 53-59

[iv] UK Prospective Study Group (UKPDS). Effect of intensive blood glucose control with metformin on complications in overweight patients with type 2 diabetes (UKPDS 34) The Lancet. Vol 352, September 12, 1998

[v] Diabetes Control and Complications Trial (DCCT) Research Group. The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. The New England Journal of Medicine. Vol 329: 14. September 30, 1993

[vi] UK Prospective Diabetes Study Group (UKPDS). Tight blood pressure control and risk of macrovascular and microvascular complications in type 2 diabetes (UKPDS 38). BMJ Volume 317, 12 September 1998

7. Department of Health (2001) National Service Framework for Diabetes: Standards Department of Health

8. Department of Health (2003) National Service Framework for Diabetes: Delivery strategy Department of Health

9. Scottish Executive (2006) Scottish Diabetes Framework – Action Plan Scottish Executive NHS Scotland

10. Clinical Resource Efficiency Support Team and Diabetes UK (2001) Taskforce on Diabetes

11. Welsh Assembly Government (2003) Improving Health in Wales National Service Framework for Diabetes in Wales Welsh Assembly Government

12. Diabetes UK and Department of Health (2006) Care Planning in Diabetes Department of Health http://www.diabetes.org.uk/Professionals/Shared_Practice/Care_Topics/Patient_held_records_and_care_planning/Care_Planning_Care_Recommendation/