

Recommendations for National Contact Points

Arising from the EPF series of Regional Conferences 2013-14

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Contents

1. Introduction	3
2. Ideal National Contact Point “Checklist”	4
3. Recommendations	7

1. Introduction

The critical role of the National Contact Points in ensuring that patients have the right information they need to make a meaningful decision about cross-border healthcare was amply demonstrated during the conferences. A number of NCPs participated in the conferences and presented their services, and during a dedicated breakout session participants brainstormed together on what an ideal NCP would look like.

Overall the NCP “landscape” is still very uneven, with wide variations in the practical interpretation of their core functions and therefore in the allocation of resources and visibility. From a patient’s perspective, it appears that some member states regarded the NCP as an afterthought to formally comply with the Directive, rather than a meaningful structure to help patients and citizens navigate a very complex web of interlinking systems. Other NCPs may have the willingness to provide a comprehensive service but have limited financial means.

As can be seen from the “checklist” below, patients have high expectations. The prevailing sentiment is that the NCP must be a “gateway to healthcare” and not a gatekeeper blocking access. Rather than behaving like a government bureaucracy, the NCP should have at its disposal the skills, knowledge and attitudes to put the patient first, to serve patients, professionals and policymakers, and to work with the patient. The aim should be that patients receive the care that they need, in a timely fashion, without adding to their burden and that the existing inequalities between patients are alleviated.

Clearly, funding of the NCPs is of vital importance – many member states seem not to have allocated any dedicated budget. In some member states the NCP actually consists of one single person, while in others (a minority) it is a large structure with many employees to provide services to patients.

Based on the feedback from patients, EPF believes that not only is it crucial to have EU-wide guidelines on how NCPs should function and provide information to patients, but it is also necessary to explore possible mechanisms to support a sustainable network of NCPs from EU funds as well as member states’ budgets.

2. Ideal National Contact Point “Checklist”

Fundamental principles

- The NCP adopts a multi-stakeholder approach. It cooperates with the domestic social security system, patient groups and professionals, as well as treatment providers abroad and with NCPs across Europe.
- The NCP demonstrates independence and transparency in its functioning, even if it is formally part of the government structure. It should have a specific mandate and operational budget and be independently appraised for its performance.
- The NCP prioritises the protection of the patient’s interests over other interests.
- The NCP’s prevailing culture is one of providing a service to patients across their entire journey, helping the patient to manage hurdles and providing solutions rather than just providing information.
- The NCP is supportive, co-operative, customer-oriented, friendly and reliable.
- The NCP adopts a high degree of professionalism and empathy; it has personnel trained in dealing with patients, and includes (volunteer) expert patients.
- The NCP provides a human response, being able and willing to take time to listen to patients and offer solutions; it acts as a patient’s advocate, offering advice on rights, helping to “read between the lines”, and acts as a mediator towards healthcare providers and authorities.
- The NCP respects human dignity and is non-discriminatory, respecting cultural differences and ensuring equal access and quality of service all.
- The NCP is able to offer informed assistance regarding rare diseases and specialised treatments.
- The NCP works with other stakeholders to identify and implement solutions to mitigate patients’ financial difficulties regarding upfront payment, thus upholding the principle of equity of access based on needs, not means.

Operation

- The NCP has transparent procedures and clear timelines.
- The NCP process provides for individualised guidance with case managers.
- The NCP communicates also with advocates and/or legal representatives nominated by individual patients.
- The NCP facilitates the translation of documents.
- The NCP supports the patient in his/her contact with foreign bodies and legislation, by liaising with other NCPs, e.g. in facilitating patient access to specialist treatment, playing a mediating role and providing solutions.
- The NCP offers patients support and advice in case of complaints, problems with reimbursement and refused authorisations.
- The NCP maintains a list of patient organisations in the country and makes this available.

- The NCP acts as a one-stop agency towards the patient, as opposed to referring enquiries to other government authorities or agencies.¹

Accessibility and visibility

- The NCP is highly visible, easy to find and to contact, ideally with a name that is easy to recognise.
- The NCP communicates using simple language that all patients can understand.
- The NCP provides information in foreign languages, at least English and relevant minority languages as well as ideally the language(s) of the most common cross-border flows.
- The NCP is accessible in real-life situations, not just via its website or only during office hours.
- The NCP can be accessed via multiple channels – website, email, free telephone line, 24-hour emergency hotline, as well as physical premises with barrier-free access for personal consultations.
- In member states with significantly large rural or dispersed populations there are regional contact points in addition to the central NCP.

The NCP website:

- ✓ is easy to find through Google
- ✓ is easy to navigate
- ✓ has content that is informative and clearly structured
- ✓ includes visual tools where appropriate, such as infographics and video
- ✓ includes real patients' stories and testimonies
- ✓ includes FAQs, guides and checklists
- ✓ includes a simple mechanism for patients to submit applications
- ✓ has an interactive feedback facility
- ✓ links to other relevant websites, such as the national health authorities, health providers and patient organisations.

Quality of information

- The information provided is accurate, reliable, up-to-date and easily understandable to lay people, “designed for and by patients”.
- Simple step-by-step guides on the application processes are available to the patient, with clear information on how to apply, how long the process will take, etc.
- Frequently Asked Questions are provided online and via printed leaflets.
- The NCP provides customised information packages for specific conditions or disease groups.
- The NCP collaborates with other NCPs to provide information on ongoing clinical trials.

Quality standards

- The NCP answers all normal enquiries within 1-2 weeks and includes a “fast-track” option for emergency situations.
- The NCP has in place a continuous improvement system including training of staff.
- The NCP is assessed for its performance independently from the national authorities.

¹ In some countries, such as Belgium, patients are referred to their healthcare insurance fund for personalised advice since this is the entity in Belgium that knows the most about the patient's file. In such cases it makes sense to avoid duplication, but the process and structure should be clear and transparent to the patient.

- A quality control system is in place to monitor performance indicators such as: response time to applications; accuracy and patient-friendliness of information; and whether the service meets patients' needs.
- The NCP is able to give a clear explanation of all decisions.
- The NCP has an effective complaints management and feedback process.
- The NCP seeks feedback from enquirers on its performance and the quality of information provided. It acts on this feedback, aiming for quality assurance.
- The NCP collects data, including numbers of enquiries, timing of outcomes, proportion of acceptances/refusals, volumes and direction of traffic for specific cross-border treatments, safety and quality, etc., and highlights any gaps and dysfunction to the national and European authorities.

3. Recommendations

1. NCPs should hold annual meetings with patient organisations at the national level to review the situation and plan on how best to work together to resolve practical issues arising from different aspects of the patient journey.
2. European-level dedicated funding should be made available to support the functioning of NCPs, particularly in resource-poor member states.
3. Standardised templates should be developed at EU level for all types of forms required in cross-border healthcare
4. Harmonisation of methods and functions of NCPs should take place across member states to achieve equality in the patient experience across the EU.
5. For meaningful and comparable information, interoperability of databases should be ensured. Data being collected nationally by individual NCPs could be used to create a centralised database of information at European level that could be used by NCPs and the European Commission.

