January 2012

Public consultation on measures for improving the recognition of prescriptions issued in another Member State

Introduction

A General information about you

A.1 Please, enter your name and, where relevant, the name of the organisation you represent.

Joint contribution from the European Region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA-Europe) *[Transparency Register ID 11977456675-84]* and Transgender Europe (TGEU). Sophie Aujean, Policy and Programmes Officer, ILGA-Europe; Richard Köhler, Policy and Capacity Officer, TGEU.

A.2 Please include also your E-mail address for contact purposes. This is for use only if we need clarification about your response.

sophie@ilga-europe.org and richard@tgeu.org

A.3 I am replying as / on behalf of:

ILGA-Europe and Transgender Europe (as indicated in A.1 above).

A.5 Please indicate which group you represent/belong to (maximum of one choice)

NGOs representing lesbian, gay, bisexual, trans and intersex persons. However, we have consciously restricted the focus of this submission to those persons who are prescribed cross-gender hormones on grounds of their gender identity.

Patients/Consumers	
A.8 Please indicate your country or, where relevant, the geographical area you represent	European Union member states and accession countries.
A.9 We will publish your response, together with your identity, on the Commission website, where it will be publicly accessible. Though if you	We welcome the publication of our contribution referring to both organisations.

request it, publication will be anonymous. How would you prefer your contribution to be published, if at all?	

B Issues in the recognition of cross-border prescriptions

Authenticating the legitimacy of the prescription	Information received from member organisations indicates that a number of transgender people were asked by dispensers why they were prescribed cross-gendered hormones before the dispenser would hand the medicine over to them. It is worrying that trans persons are on such occasions obliged to explain why they need to take specific treatments in link with their gender reassignment treatment. In addition, some organisations reported obstacles faced by transgender people when trying to get hold of the necessary medication in another EU member state. One such example was reported with regard to a Danish trans woman living in Germany, (close to the Danish border) and who was told by a German dispenser to see a German doctor and to get a German prescription. Contradictorily, a German trans person residing and working in Belgium went to a hospital in Belgium asking for an injection of his regular testosterone shot. He was denied this service and told that he would need a certificate from a German doctor proving that this injection was necessary.
Authenticating the entitlement of the prescriber	n/a
Understanding the language the prescription was written in	n/a
Understanding prescriptions that are hand-written	Non hand-written prescriptions would ease the identification of the products and are hence preferred.
Dispensers having insufficient information on the prescription for their national (legal) requirements	We believe that dispensers may lack information as to whether they are authorized to hand over medicines, and all the more, hormones, prescribed in another member state.

The prescribed drug and/or device not being available on the local (national) market In case substitution is possible: no suitable alternative drug or device being available on the local (national) market	A number of problems with regard to the availability of the products prescribed were reported. Some member organisations reported problems related to the lack of promptness of the dispenser to actually provide the products. Given that such medical requests are time-sensitive, a delay may have a considerable impact on the treatment of the patient. Others said that for many medicines, there were no alternative products having exactly the same quality or the same dosage in the host country. Again, given the sensitive nature of hormonal treatment changing the carrier substance or dosage may inflict the persons' health severely. Some concrete examples of products not available in other EU Member States were mentioned (list below is not exhaustive): - DHEA-S gel pills and Estrogen gel prescribed in Belgium are not available in Dutch pharmacies. - *Androcur* (estrogen) products prescribed in Spain where not available in Sweden. - *Sustanon*, a testosterone product, has suddenly ceased to be produced in Belgium and in the United Kingdom, even though trans men (female-to-male trans persons) very much depend on this product. There is no other 3-month testosterone depot product produced or available in Europe. As a result, many trans persons need to get these products in other countries where there are still supplies (e.g. Netherlands and Spain).

B.2 Which other elements could cause problems in the dispensing of cross-border prescriptions?

Dispensers disapproving of gender reassignment treatment might deny handing out of cross-hormonal products.

C Identifying the prescribed product

C.1 Which elements in prescription forms contribute to the identification of medicinal products?

International Non-proprietary Name (INN) / generic name	Member organisations reported that the fact that the names of the medicines were not the same in all EU member states was an obstacle

	to their identification. For example, a Spanish trans woman residing in Sweden encountered problems when she presented prescriptions for estrogen in Sweden. The pharmacist did not recognise the name of the product and could not retrieve the active substance. Prescriptions should thus comprise the list of components of the medicines, at least the active substance, prescribed.
Brand name	n/a
Form of administration	n/a
Quantity	n/a
Strength	n/a
Dosage regimen or direction for use	n/a
Intended duration of use	n/a

C.2 Which other elements could contribute to a better identifying the medicinal product?
(please check section "G Other information" first before answering this question)

Member organisations stated that it would ease the identification of the prescribed product if some form of standard reference recognised across the EU was created.

D Identifying the patient

D.1 Which elements in prescriptions contribute to the identification of the Patient?

Surname	Gendered surnames, e.g. patronymic names, may lead to confusion, if the consumer presents a prescription for cross-hormonal treatment.
First name(s) or initials	First name(s) can create similar problems as they indicate a gender that might be in contrast to the gender expression and/ or the hormonal product.
Gender	ILGA-Europe and TGEU consider that it is rather worrying to see gender as a key element of patient identification. Such form of identification happens rather frequently whereby the gender mentioned on official documents (including prescriptions) does not match the gender appearance of the patient. Such situations have been reported to cause hostility and/or suspicion of fraud from dispensers. Moreover, trans people can feel harassed by dispensers who address them

	with pronouns inappropriate to their gender e.g. 'Sir' instead of 'Madame' or vice versa.
Date of birth	n/a
Home address	n/a

D.2 Which other elements could contribute to a better identification of the patient?
(please check section "G Other information" first before answering this question)

n/a

E Improving patient understanding of prescriptions

E.1 Which elements in prescription forms contribute to a better patient understanding of what is prescribed?

Wording of dosage (written out in full, use of non-Latin terms, etc.)	Some member organisations said that it would ease transgender people's understanding of their treatment as well as the identification of the medicines prescribed if they had more information on the components of the products prescribed. Non-hand written prescriptions were also mentioned as being helpful for patients.
Use of icons (representing what time to take the medicine)	n/a
Length of treatment	n/a
Instructions for proper use (e.g. "take with food", etc.)	While instructions for use should primarily appear on the medicine itself, it would surely be useful to get more information on the prescription describing when and how medicines should be used.
Print prescriptions (instead of handwriting)	As stated above, several member organisations reported that hand-written prescriptions were an obstacle to cross-border use. This often remains the case even when the trans persons in question can clearly explain the medicines that they were prescribed.

F Identifying the prescriber

F.1 What are the main reasons to have clear prescriber identification in prescription forms (minimum of one choice)?	Trans persons may be suspected of unlawfully trying to get hold of medicine that is not intended for their own usage. For example, dispensers may fear fraud for the purposes of financial gain in the case of provision of testosterone (for body building of biological males) or estrogen. In order to avoid unnecessary suspicion, it would appear very important to have a clearly identifiable and traceable prescriber along with contact

	information.
F.2 How can prescriber authentication best be guaranteed?	n/a
Paper solutions using elements in prescriptions to identify the prescriber such as name, address, qualification, prescriber code, etc.	n/a
Paper solutions using elements in prescriptions to 1) identify the prescriber such as name, address, qualification, prescriber code, etc. AND 2) enable contact with the prescriber such as phone/fax number, email, etc.	Feedback from member organisations suggest that direct contact between dispenser and prescriber for authentication had not been sought. However, a paper solution with contact information may also help the patient to remember better the medicine (name, dosage, application routine etc).
National prescriber databases accessible to dispensers (e.g. accessed via internet) using information on the prescription as a staring point.	n/a
An EU-level prescriber database accessible to dispensers (eg via internet) using information on the prescription as a starting point.	Member organisations expressed support for an EU-wide centralised database of [cross-border] prescribers. Such a database would compliment other initiatives that are being considered by the European Commission e.g. freedom of movement of public documents and recognition of the effects of civil documents (COM(2010) 747 final).
A "paperless" e-prescription solution, eg allowing dispensers to verify information in a central repository on prescriber, prescription and patient.	n/a

F.3 Which other solutions could improve prescriber authentication?	n/a
F.4 Which elements in prescription forms contribute to the identification of the Prescriber?	

Surname	yes
First name(s) or initials	yes
Professional qualification	yes
Work address	yes
Details for direct contact with prescriber	yes
(either telephone, fax or email)	telephone, fax and email
Signature (written or digital)	yes
F.5 Which other elements could contribute to a better identification of the prescriber (optional)?	EU-centralised numeric identification system that is preferably used also on the national level to identify cross-border prescribers (and thus minimise reluctance to accept prescriber's authenticity).

G Other information

G.1 Which other information is necessary in prescriptions?	
Indication for prescribing	n/a
Date of prescription	yes
Period that prescription is valid	yes
Generic substitution possible (yes/no)?	yes
G.2 Which other elements would you add?	n/a

H Comments

H.1 Please include any additional comments you might have (max. 5000 characters) or upload a document (max 1 document, if possible in MS Word, pdf or rich text format). In exceptional cases and only if you experience problems with this questionnaire, you can also send us documents by email (SANCO-cross-border-healthcare@ec.europa.eu).

The scope of this submission explores experiences of cross-border health care with regard to availability of cross-hormonal products for transgender costumers. Cross-hormonal treatments require life-long application in regular intervals of the same active substance and preferably the same carrier substance. The examples provided reflect common problems and solutions towards the need of maintaining one's hormonal treatment when being abroad.

The fact that some dispensers deny products to transgender patients on the basis that they disapprove of gender reassignment treatment is particularly worrying. Concrete as well as perceived experiences of discrimination are a driving factor leading to black-market purchases (via the internet or through cross-border imports). Additionally, self-medication without professional supervision (which in some instances can happen over extended periods of time) may lead to serious health problems.

Our member organisations reported extensive lack of knowledge within the trans community about cross-border healthcare in general and the possibility of getting medicines prescribed in another Member State in particular. Numerous trans people are simply not aware that prescriptions obtained in one EU country are valid in other EU countries. The need of better informing patients regarding their rights in this regard has been formulated by many. Concrete knowledge providing measures would thus help to facilitate freedom of movement of the trans community.