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ORIGINAL ARTICLE

Raising awareness of unspecified living kidney donation: an ELPAT* view

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ABSTRACT

Background. Living donor kidney transplantation (LDKT) is the preferred treatment for patients with end-stage renal disease and unspecified living kidney donation is morally justified. Despite the excellent outcomes of LDKT, unspecified kidney donation (UKD) is limited to a minority of European countries due to legal constraints and moral objections. Consequently, there are significant variations in practice and approach between countries and the contribution of UKD is undervalued. Where UKD is accepted as routine, an increasing number of patients in the kidney exchange programme are successfully transplanted when a 'chain' of transplants is triggered by a single unspecified donor. By expanding the shared living donor pool, the benefit of LDKT is extended to patients who do not have their own living donor because a recipient on the national transplant list always completes the chain. Is there a moral imperative to increase the scope of UKD and how could this be achieved?

Methods. An examination of the literature and individual country practices was performed to identify the limitations on UKD in Europe and recommend strategies to increase transplant opportunities.

Results. Primary limitations to UKD, key players and their roles and responsibilities were identified.

Conclusions. Raising awareness to encourage the public to volunteer to donate is appropriate and desirable to increase UKD. Recommendations are made to provide a framework for increasing awareness and engagement in UKD. The public, healthcare professionals, policy makers and society and religious leaders have a role to play in creating an environment for change.

Keywords: donation, ethics, kidney, living, unspecified

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Table 1. UKD activity by country^a

Country	Living donor transplants as a percentage of all transplants ^b	Total number of unspecified kidney donors (at December 2018)	Unspecified donors as a percentage of all living donors	Year of first UD
Czech Republic	11 (n = 51)	5	0.9	2008
Italy	14 (n = 313)	7	0.6	2015
The Netherlands	56 (n = 551)	160 ^c	1.5 ^c	2000
Spain	10 (n = 332)	13	0.5	2011
Sweden	26 (n = 125)	26	1.5	2004
UK	29 (n = 1000)	699	8	2007

^aCountry-specific UD data courtesy of co-authors (the Netherlands, Sweden, UK) and personal contacts, Jiri Fronek (Czech Republic); Paola di Ciaccio (Italy); M.O. Valentin (Spain).

^bFrom Transplant Newsletter 2017 [2].

^cData from the largest single centre (Rotterdam) only. All centre data not available for the Netherlands.

INTRODUCTION AND BACKGROUND

Living donor kidney transplantation (LDKT) is the preferred treatment for patients with end-stage renal disease (ESRD); both recipient and graft survival are excellent and better than for deceased donor organs [1]. The concept of healthy volunteers donating an organ to a family member or loved one has become routine in many countries and represents a philosophical shift in clinical practice [2]. The increasing contribution of LDKT worldwide indicates that, within appropriate frameworks and agreed boundaries of best practice, it is considered morally acceptable and healthcare professionals are committed to it [3–5]. Proponents of LDKT actively engage with loved ones to seek transplant opportunities for their patients, promoting strategies and interventions to create equity of access across all sectors of society, regardless of ethnicity, religion or culture [6–9].

Approaches to living organ donation (LOD) vary between countries according to national policy, which influences access to deceased donor kidney transplantation and LDKT and informs rules about donor protection, public awareness campaigns and education programmes. The lack of universal support, both legally and philosophically, for unspecified kidney donation (UKD) is striking [3]. Scepticism about the motivations of the healthy volunteer ‘altruistic donor’ remains at the core of legal and social policies but, there is no evidence that UKD is detrimental to the donor or society [10–12]. In most European countries that support LOD, ‘relatedness’ between donor and recipient (specified donation) is legally mandated [13–15]. The genetic and/or emotional relationship between donor and recipient has provided historical moral justification for LOD, and the absence of such relationships in unspecified donation (UD) has made some countries reluctant to adopt a legal framework to support it [3].

In the Netherlands and UK, where there has been a significant expansion in UKD, an increasing number of patients in the kidney exchange programme are successfully transplanted when a ‘chain’ of transplants is triggered by a single unspecified donor. UKD is also permitted in other countries, including Sweden, Spain, Italy, Czech Republic, Austria and Finland, but activity remains low and is poorly differentiated in global reports [2]. Table 1 shows activity from countries where it has been possible to obtain UD data through personal contacts [2, 3]. In the Netherlands, unspecified donors are encouraged to enter the national kidney exchange programme but may be matched locally in a ‘domino chain’ or to a recipient on the national waiting list if they prefer not to travel to another centre. Any number of matches can be identified in a single exchange provided that

multiple donor and recipient operations can be performed simultaneously. Simultaneous matching runs for unspecified donors and the kidney crossover programme have recently been introduced and the donor usually travels between the donating and receiving hospitals. There is no apparent impact on outcome if the kidney, rather than the donor, travels [1].

In the UK, unspecified donors enter the United Kingdom Living Kidney Sharing Scheme (UKLKSS) to initiate a chain of up to three transplants from a single donation unless there is a high priority recipient on the national transplant list to whom they donate instead. Simultaneous matching runs for altruistic donor chains and paired/pooled donations are preferred but non-simultaneous surgery is also permitted to overcome logistical challenges such as theatre availability. The UK algorithm for allocation of deceased donor kidneys is used to identify a single recipient on the national transplant list either to complete a chain or for donors who do not enter a chain. Typically, the donated kidney travels to the recipient receiving centre.

The contribution of UKD to the shared living donor pool is invaluable, particularly for long-waiting patients with immunological complexity due to high levels of human leucocyte antigen antibodies and recipients from Black and Asian minority ethnic (BAME) communities [1, 16, 17]. The utility of this approach provides a distinct and important reason to support UKD.

In the Netherlands, UD accounts for ~1.5% of living kidney donors in the largest single centre performing LDKT (Table 1). These donors, together with those who donate anonymously to a ‘paired recipient’ in the kidney exchange programme, account for 17% of the national living donor pool [18]. In the UK, despite a fall in the absolute numbers of unspecified donors, they account for 21% of transplants within the UKLKSS by donating into a ‘chain’, which is an increasing trend [1]. Increasing activity has stimulated research and informed national strategies to support clinical programmes [12, 17, 19, 20]. The role of publicity and media in influencing the public and their willingness to donate has been evident. Global access to communication through the Internet and social media has prompted offers of donation from non-residents without access to UD in their own countries, generating a need for clear guidance and agreed policies to support clinical practice [21–23].

UD is not organ-specific but is predominantly UKD, reflecting clinical preference for kidney rather than lobe of liver donation in countries where UD has evolved. The perception of risk for the living liver donor has undoubtedly influenced activity—the UK and the Netherlands report cases of unspecified liver donors representing <1% of UD activity [1, 18]. Unspecified liver

Table 2. Primary limitations to UKD and key players

Primary limitations	Key players
(i) Lack of legal framework, infrastructure and resources to support LOD ± UD	Policy makers Competent authorities Commissioners
(ii) Ethnicity and culture	Society and religious leaders Public, donors, recipients and families
(iii) Low societal awareness of options for LOD	Society and religious leaders Public, donors, recipients and families Patient/donor associations Media
(iv) Risk aversion—'do no harm'	Policy makers Commissioners Procurement organisations Healthcare professionals Professional societies

donation may be seen as an unwelcome consequence of a UD programme; conferring more risk on the donor, creating opportunities for 'serial' UD and adding further clinical and moral complexity to a controversial practice [11].

This article focuses on UKD to examine the limitations of UD in Europe and to recommend strategies to increase transplant opportunities for patients with ESRD by:

- (i) raising awareness and
- (ii) engaging with key audiences.

These recommendations reflect experience from countries where engagement initiatives have been successful in achieving an ethical expansion of the living donor pool and UKD activity. Successful implementation depends upon the maturity and characteristics of individual LDKT programmes. Appropriate infrastructure, organisational frameworks and clinical pathways must be established to facilitate donation and safeguard the interests of people who volunteer to donate.

LIMITATIONS AND KEY PLAYERS

Table 2 identifies the primary limitations to the development of UKD. The categories are interdependent and influenced by key players, who shape and define the environment, culture and infrastructure that supports national LOD and UKD programmes.

The key players are classified into those:

- (i) Specifically dedicated to UKD (e.g. previous living donors and donor associations)
- (ii) With a generic role within transplantation, from a clinical (professionals), legal and organisational (competent authority and procurement organisations) or wider community (government, media, religious and society leaders) perspective.

By identifying the barriers and understanding their source and impact, we have defined scalable recommendations to overcome them.

Legal framework, resources and infrastructure

The scope of LOD and UD is inevitably curtailed where the prevailing national view is non-permissive [2, 3]. There are legal

prohibitions on LOD in all European Union countries to safeguard potential donors from coercion and reward and to protect vulnerable people from organ trafficking [3, 4, 23]. Arguments that underpin legal limitations solely on the basis of the relationship between donor and recipient exist in many European countries [3]. Such restrictions preclude UD and argue for donor protection, primarily on the basis of non-maleficence and voluntariness, rather than objective criteria such as an individual's physical and psychological suitability to donate.

These prescriptive limitations presume that a close or valued donor–recipient relationship, where the donor is 'altruistically' motivated by recipient benefit, provides a 'core of acceptability' to an act of donation. While the impact of recipient benefit may be true, there is a 'spectrum of altruism'—including self-interest, reciprocity and obligation—associated with donation between family members and friends that is considered morally acceptable. This 'spectrum' does not detract from the typically selfless act or from the sense of personal and individual identity that motivates loved ones to donate but, realistically describes the motivation and moral complexity that underpins decision-making in LOD [24]. The morality of an individual's decision to donate is determined by the intrinsic value and integrity of the decision itself. The moral code that guides 'all' donors is complex, but relationships based upon genetics, love or emotion do not provide the only legitimate reasons to donate. For unspecified kidney donors, the 'core of moral acceptability' associated with close donor–recipient relationships is absent but the act of UD to an anonymous recipient is, 'prima facie', more selfless than donation to a spouse or partner or even to a child. There is no reciprocity for the unspecified donor as there is within a shared relationship, or sense of obligation when a parent donates to a child. Obligation has many guises: 'absolute' (between parent and child), 'relative' (the desire to help a spouse, partner or friend), almost 'theoretical' (in the context of an estranged family member). A sense of moral obligation (to help someone in need of a transplant) from the unspecified donor is no less laudable because his/her recipient is anonymously identified. Yet, UD is still viewed with scepticism, placing an increased burden upon donors to provide legal and moral justification for their wish to donate.

Without a legal mandate, there is little incentive to develop the necessary infrastructure and resources to support a LOD programme but, in countries where there is a permissive legal framework, establishing sufficient capacity and capability to fulfil the LOD potential can also be a challenge [19, 25].

Ethnicity and culture

There is little published data available about ethnicity and culture in the specific context of UKD, but the latest statistics from National Health Service Blood and Transplant (NHSBT) shows UK trends within BAME communities [1]. Unspecified donors are typically White, aged between 50 and 85 years (median 50 years) with equivalent numbers of male (51%) and female (48%) donors. About 14% of the UK population is from BAME communities but only 1% of unspecified donors are from these communities, with more Asians than Blacks donating. Although 25% of unspecified donor kidneys are transplanted into BAME recipients and 24% receive kidneys through kidney exchange programmes [1], people from BAME communities are more likely to donate to family or friends than to society [6–9].

The need for and reduced access to kidney transplantation for BAME populations is well documented due to predisposition to kidney disease, cultural and religious beliefs and potential

barriers to communication [1, 8, 9, 26–28]. Different approaches, adapted to social demography, community subsets and their specific beliefs and cultural needs, are necessary to encourage engagement about donation and transplantation. Home education, in conjunction with hospital-based interventions, has been successful in the Netherlands and USA to improve engagement and understanding between healthcare professionals, patients and their families [6–9]. Given their predisposition to lifelong risk of kidney disease, living donors from these communities must be selected carefully, which is reflected in UK best-practice guidelines [29]. This should not preclude awareness campaigns and public engagement initiatives to inform them about the potential benefits of LOD and UKD and its contribution to the overall transplantation programme.

Low societal awareness

Even in countries where UD is an accepted norm, public awareness is poor (Kantar Public) and there may be reticence to address it. In contrast to the approach to deceased organ, tissue, blood and bone marrow donation, promotional campaigns to actively engage with all sectors of society are not routine. To understand these differences, it is helpful to define the terminology and understand the implications in the context of LOD.

Promotion is defined as actions to deliver a specific outcome [30]. This may include encouraging progress of a particular issue or idea in the case of deceased organ donation; it is appropriate to 'promote' an increase in donation rates to create transplant opportunities. Promotion is also used to encourage sales (of a product) through active marketing or advertising and/or by securing financial support. In this context, promotion of LOD through targeted public campaigns may have negative connotations such as solicitation, coercion, commercialisation and commodification. These are not aligned with the concept of 'a gift, freely given'.

The principle of donor protection—safeguarding every volunteer donor, proportionate to the risk—is fundamental to how the promotion of LOD and particularly UD is perceived. The 'hierarchy of acceptability' relates to how 'routine' or 'exceptional' a practice is and, hence, the balance of risk associated with it. The willingness to promote lower risk activities with increased utility such as blood donation and deceased organ donation is greater than for activities that are believed to carry higher risk, even if there is proven benefit. In LOD, this includes considerations about the type of organ that is being donated and to whom, individual donor risk versus recipient outcome, and reputational risk to the overall organ donation and transplantation programme.

The relationship between the learning curve and the willingness for procurement organisations and healthcare professionals to actively promote LOD is apparent: even in established programmes where clinicians actively endorse specified donation with friends and family, there is variable enthusiasm for UD [1].

In contrast to promotion, raising awareness provides knowledge and information to support choices, autonomous decision-making and free and voluntary consent [30–33]. For these reasons, raising public awareness has advantages over active promotion in the context of LOD, and especially UD, where donors volunteer from all sectors of society. It creates opportunity to provide public information programmes that reinforce the principles of LOD, supports the rights of the person choosing to donate and removes ambiguity about public solicitation or targeted recruitment of potential donors [22, 34, 35]. A survey

commissioned by NHSBT in January 2017 (Kantar Public) showed that 52% of the population were 'unaware' of living kidney donation but having been 'made aware', 62% of people considered donating to a family member or friend and 22% to someone they did not know (Kantar Public).

The distinction between promotion and raising awareness, in terms of outcome, is narrow; both aim to encourage public engagement and organ donation. However, the principle of free and informed choice lies at the heart of LOD and UD is breaking boundaries of international clinical practice. A process driven by donor choice, rather than one promoted by healthcare professionals and organ procurement organisations, inspires confidence and engagement from the public, wider transplant community and policymakers.

Risk aversion—'do no harm'

In countries where UKD is well established, it is a 'donor-driven' process. The willingness of clinicians to actively promote LOD to family and friends in comparison with UD is akin to the early days of LDKT, before it became fully embedded. The UD programme remains a learning curve, and is typically perceived as higher risk, in comparison with specified donation, because of it.

There is inherent risk of death and comorbidity associated with LDKT, reflected in European and national guidelines. Careful preparation and assessment of all donors are recommended to ameliorate risk [5, 21–23, 27, 33]. The role of donor-recipient relationships in defining relative risk or motivation to donate has already been discussed and, in itself, should not be a barrier to donation. For example, there is no evidence to suggest, in the case of two living kidney donors—one donating directly to a family member, the other anonymously—both clinically suitable to donate, with identical characteristics and equivalent surgical risk, that one is more exposed to physical harm than the other. In terms of psychological harm, there is limited evidence available but a lack of emotional proximity to the recipient does not appear to be detrimental to the donor [11, 12, 20, 24, 36, 37]. Anecdotally, unspecified donors often cite this as a 'positive' benefit, absolving them of any emotional obligation beyond the act of donation. The voluntary nature of UD is potentially less equivocal than specified donation, where the 'spectrum of obligation' owed to a family member or identified recipient is more likely to invoke concerns about coercion and reward.

Initially, professionals were sceptical about UD, questioned donor motivation and were reticent to engage with the programme. Concerns about reinforcing narcissistic behaviour and impact on long-term health added to the unease [10, 15, 20]. As UKD has become more routine, it has become increasingly accepted. There is little published literature examining the attitudes of healthcare professionals but there is anecdotal evidence in the UK to suggest that kidney transplant professionals perceive UD differently from specified donation. The potential harm caused to patients on the waiting list, deprived of the opportunity for transplantation due to limitations on UD, does not appear to counter concerns about UKD *per se*. A multi-centre prospective cohort study is in progress in the UK to better understand the barriers to UD [25].

An unintended consequence in countries with active UKD programmes is to encourage donor offers for previously unknown, specified recipients. These are often identified through personal campaigns or stories posted on social media. Social media raises the 'fear factor' because it blurs the boundaries

between raising awareness, advertising and offering payment for LOD [35]. At a practical level, specified donation to a previously unknown recipient, while legally permissible, remains controversial and a challenge to the clinical community [38]. The concern is that, if every donor 'chose' their recipient, there would be an unfair distribution of these typically high quality living donor organs and other suitable recipients would miss out on the chance of a transplant. The counter argument is that every additional donation removes a patient from the waiting list and reduces overall demand for a scarce supply of suitable kidneys for transplant. In the UK, few cases of social media-driven specified donations have come to fruition, but each recipient appeal generates a high number of self-referrals from potential donors, which is resource intensive and requires effective management. Donors who are incompatible with their 'specified' recipient may consider UKD instead. Clear consensus guidelines are helpful in agreeing a consistent approach and educating donors and recipients is essential to manage their expectations [39].

Another unintended consequence of UKD is the interest generated in UD of other organs such as lobe of liver. Taking UD beyond kidney donation is controversial and raises the possibility of 'serial' organ donation in a single donor [11]. Again, consensus guidelines are needed to define possible adverse consequences and to support transplant teams to foster best practice in these complex cases [40].

DEFINING THE AUDIENCES

To create change, there must be a sense of urgency and an environment to facilitate change. Failure to engage with the concept of UKD denies healthy volunteers the opportunity to donate and patients miss out on the chance of a successful kidney transplant and freedom from dialysis. This is an urgent problem. Using the primary limitations as our focus, different audiences were defined amongst the key players according to their individual roles and responsibilities (Table 3). By understanding the information needs of the different audiences and targeting information appropriately, recommendations could be made for use in European countries to improve awareness and facilitate engagement. Audiences are identified as:

- (i) targets—those to whom awareness initiatives about UKD are directed and
- (ii) influencers—those who work to bring about change at an individual, institutional or societal level.

Target audiences

The public audiences are defined by how much they have directly or indirectly been exposed to or engaged with LOD and/or the healthcare system. For each of these audiences, the approach needs to be sensitive to social demography, circumstances, culture and beliefs and tailored to previous knowledge and experience. The general public need messages to raise overall awareness and to address issues of trust, concern and scepticism. The interested public are more likely to respond to an appeal that sparks a latent desire to do something good for someone else [12], while the engaged public will have more complex information needs, depending upon their previous knowledge and experience as patients or family members.

Healthcare professionals working across all sectors are both 'targets' and 'influencers' and are well represented within cohorts of unspecified donors. Professionals working outside

organ donation and transplantation, particularly in primary and secondary care, may not have specialist knowledge but will provide advice and/or act as initial points of contact for people considering donation. To enable them to raise awareness and respond appropriately to expressions of interest from the public, they represent a target audience with specific educational needs.

Professionals working in the field of donation, transplantation and nephrology fall into both audiences; they are all 'influencers' but depending upon their specialism or proximity to transplantation may require education and training to keep them updated. As ambassadors and advocates for their patients, their active participation is necessary to ensure consistent messaging, inspire public confidence and engage with public awareness campaigns [24]. Conflict can arise if clinicians have personal views about LOD and UKD, which influence their clinical practice. Strong views about particular groups of people based on age, ethnicity or motivation may impact upon the acceptance of referrals and donor satisfaction, and jeopardize the reputation of the programme. Early involvement and collaboration, and consistent, best practice guidelines are important to engage and update clinicians [21–23, 33, 39].

The development of UKD has provided rich opportunities for research. Retrospective studies provide insight into the early experience of UD and inform approaches to publicity and target audiences [3, 12, 14, 20, 24]. Further prospective research will inform future guidance and discussion in this rapidly evolving area of LOD practice [25].

Influencers

Healthcare professionals, policymakers, competent authorities and procurement organisations are key influencers in determining the environment to facilitate LOD and UKD, overcome barriers to acceptance and support increases in organ donation activity. Prompted by a change in the UK law in 2006 [41, 42], the wider transplant community worked together to mirror the success of the programme in the Netherlands [17, 18]. More than 500 people have since donated as an unspecified donor and an increasing number donate into an altruistic donor chain in the UKLSS [1].

A key driver in the development of the UK programme was the formation of the 'Give a Kidney' charity (www.giveakidney.org), founded in 2011 by unspecified donors and transplant professionals with advisory support from NHSBT, the organisation with responsibility for organ procurement. The charity was unique in Europe, but a similar group has since established in the Netherlands. 'YouGov' polls performed in 2011 and repeated in 2014 demonstrated that the public's willingness to consider UD increased by 3% (from 8% to 11%) and awareness about UKD increased from 67% to 79% in the lifetime of the charity, while donations from UKDs increased exponentially (from 34 to 118 donors per year) [1].

The activities of the charity and the collaborations with NHSBT, transplant professionals and the wider NHS helped to maximise UKD activity across the UK. The willingness of Trustees to work alongside healthcare professionals dispelled initial scepticism and achieved credibility and support for the contribution that the charity makes to the UKD programme—their ability to generate media and publicity opportunities through case-based stories has proved invaluable to public awareness campaigns alone. Such collaborations create momentum for change, modify behaviours and inspire the whole organ donation and transplantation community.

Table 3. The audiences: targets and influencers in UKD

Audiences	
Targets	Influencers
(i) General public Society; wider public with limited or no knowledge of LDKT UKD	(i) Healthcare professionals Transplant teams Non-transplant nephrology teams Transplant centres/referring nephrology units Professional societies/associations
(ii) Interested public People inspired to volunteer to donate, for example, by their own life experiences	(ii) Recipients and donors Previous transplant recipients Previous unspecified/specified donors Recipient and donor organisations
(iii) Engaged public, potential transplant recipients, donors and family members already within the kidney care/transplantation setting	(iii) Policy and law makers, government Health and Justice departments, competent authorities, procurement organisations
(iv) Healthcare professionals, non-transplant/nephrology multidisciplinary colleagues across primary, secondary and tertiary care	(iv) Role models, religious leaders, politicians, respected public figures (v) Media International, national, regional, local Social media Proactive/reactive

Media interest wains once the novelty of UKD diminishes, which must be balanced against the greater good that is derived from UKD becoming 'the norm'. For an emerging programme, national news stories—television, radio, Internet and press—create immediate impact and encourage potential volunteers to 'consider' donation [12]. Thereafter, frequent local or regional stories remind people to put their thoughts into action and initiate the process. Donors of any age are inspired by publicity, regardless of whether it is specifically targeted to their own age group or not. Young people and UKD are controversial and although people of 18–29 years often express interest in donation, fewer in this age range proceed. This may reflect general concerns about lifelong risk following kidney donation, influencing both the approach of transplant professionals and a higher rate of donor withdrawal from this age group after counselling.

CONCLUSION

This article has explored the approach to UKD across Europe and identified the primary limitations to increasing donation from volunteer donors to create more LDKT opportunities for patients as a treatment of choice for ESRD. In particular, the

potential for unspecified donors to initiate a chain of transplants in the kidney exchange programme significantly benefits long-waiting patients with immunological complexity, from BAME communities and those who do not have a suitable living donor of their own.

Raising awareness to improve knowledge and understanding across all sectors of society, which encourages the public to volunteer to donate, is appropriate and desirable to increase UKD. The following recommendations provide a framework that individual countries can adapt to overcome the primary limitations to UKD and secure commitment from all the key players to create an environment for change.

RECOMMENDATIONS

- (i) Countries wishing to undertake UKD must have a legal framework to support LOD and be committed to LDKT and UKD. Appropriate infrastructure, organisational frameworks and clinical pathways must be in place to facilitate donation whilst safeguarding the interests of people who volunteer to donate.
- (ii) UKD offers the best opportunity to maximise transplant opportunities for patients with ESRD through kidney exchange programmes (donor chains).
- (iii) Raising awareness by providing stratified information that is country-specific, culturally sensitive and relevant across all sectors of society offers a sustainable option for increasing UKD activity.
- (iv) The content and context of raising awareness initiatives must be appropriate for both mature and emerging programmes and relevant to all target audiences.
- (v) Collaboration between dedicated groups—previous unspecified kidney donors, healthcare professionals and procurement organisations—is the most effective model for engaging with target audiences.
- (vi) Competent authorities with support of dedicated groups are best placed to achieve legislative change in individual countries.

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CONFLICT OF INTEREST STATEMENT

None declared.

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