Joint Action on integrating prevention, testing and linkage to care strategies across HIV, viral hepatitis, TB and STIs in Europe

Partner Notification usefulness Technical Report

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1. Introduction

The INTEGRATE Joint Action seeks to increase integrated early diagnosis and linkage to prevention and care of HIV, viral hepatitis, tuberculosis (TB) and sexually transmitted infections (STIs) in EU Member States. One component of the joint action is examining active case finding, called partner notification (PN) or contact tracing (CT), which is effective in diagnosing and preventing onwards transmission and recurrent infections. Building on existing reports, Integrate aimed to disseminate evidence-based tools that could be adapted to different contexts and populations across Europe.

Throughout the project, it became clear that there were many tools available however the barriers in place for adapting and using these tools stem from a lack of knowledge of the tools and on partner notification itself, including the laws and regulations surrounding the processes and how healthcare and community health workers are legally allowed to support patients in the process of PN services. Additional barriers include a lack of training on how to conduct, lack of national guidelines and lack of resources for PN services. As these findings became clear, the focus of the partner notification work shifted to address these barriers in hopes of creating a clearer pathway for services.

This report highlights the findings from INTEGRATE partner notification and contact tracing interventions, as well as updating the latest information on best practice, key populations and laws and regulations. Throughout this report, partner notification refers to the voluntary process of a patient notifying their partners, either on their own (patient referral), assisted by healthcare providers or peers (healthcare assisted partner notification) or via a healthcare worker (provider referral) where regulations allow. Additionally, while the term partner notification is traditionally used for the process of identifying partners with STIs and HIV, contact tracing is the term used to notify contacts of patients with viral hepatitis and TB. Throughout this report, we will use partner notification/contact tracing (PN/CT) together, as it is the aim of this joint action to integrate the four disease areas.

2. Integration of Partner Notification and Contact Tracing

The INTEGRATE joint action has 29 partners from 16 different countries, with partners ranging from hospitals to research institutions and civil society organisations. The first step in understanding the partner notification environment was to survey all Integrate partners on the situation of partner notification in their country or region. Following the survey, the originally identified pilot countries (Ireland, Italy, Greece and Romania) were included in a mapping exercise, in which key stakeholders were interviewed to gain a more in-depth understanding of the PN/CT pathways. As both the baseline survey and the mapping exercise identified a need for increased awareness or creation of national guidelines for PN/CT, examples of guidelines from each country were collected, translated and included in a public online repository of documents for future reference.

2.1 Baseline survey

At the beginning of the joint action, INTEGRATE partners were asked questions related to partner notification and contact tracing in their country or region. These questions covered current practices, legal requirements, reporting, challenges, guidelines and responsibilities. As demonstrated by the first INTEGRATE partner survey, there appears to be significant levels of confusion and/or uncertainty surrounding the partner notification laws, regulations and practices in each country.¹ This is evidenced in multiple ways: conflicting responses given by respondents from the same country, a high amount of unanswered questions, many questions answered with 'I don't know', few best practice examples of partner notification, and few links/ attachments to country guidelines on PN/CT. It is important to note that these findings do not necessarily indicate that partner notification does not occur, particularly as the respondents could be answering from the point of view of their particular organization (which may not be a clinical organization involved with PN/CT) instead of the host country's operating procedures. Often respondents could outline general principle or describe how PN/CT services were carried out yet could not identify any clear systems or pathways. Instead, the responses do point to a lack of knowledge/ understanding of how or if PN/CT does or does not occur within these contexts.

Despite a lack of in-depth knowledge of how partner notification occurs, respondents were able to identify numerous barriers and challenges that impede the process. These include limited resources, limited time, limited staff, lack of guidelines, lack of patient education, confidentiality issues and stigma. Additionally, respondents noted that in order to improve PN/CT efforts, there is a need for more training of healthcare providers and CBVCT staff, introducing national guidelines on PN/CT and sharing experiences of PN/CT with other countries.

Of all the disease areas, responses to TB contact tracing appeared to be the most comprehensive and understood, with participants often identifying guidelines, documents or outlining the national procedures involved in TB contact tracing. Many partners noted that often guidelines for partner notification for HIV and STIs are combined.

Three tables summarizing country requirements for PN/CT as reported in the INTEGRATE baseline survey can be found in Annex 1. In each table, answers are highlighted that are conflicting, where partners did not know the answers, or where there was simply no information given. Portugal, Greece, Lithuania, Romania, Hungry and Croatia all experienced conflicting or lacking information for each three areas of questioning. Italy, Estonia, Poland and Spain also had conflicting information or did not know/answer in one or two areas. From the widespread highlighting, it is easy to see that there is a need to improve not only the process of PN/CT, but also the knowledge and understanding of the requirements by individuals on the ground. Establishing an argument for national guidelines on partner

¹ Respondents were all INTEGRATE partners, from clinical, educational, civil society and public health backgrounds.

otification is equally as important as improving the widespread knowledge of healthcare workers, and those adjacent to these disease areas, on the partner notification practices they can and should utilize.

2.2 Mapping exercise

INTEGRATE originally proposed to undertake a pilot project of partner notification activities in four countries: Ireland, Italy, Greece and Romania. Before planning the pilot study for WP7.2, a mapping exercise was conducted to better understand the landscape of PN/CT in the pilot countries. This mapping exercise was useful in identifying differences between policies and practices on the ground, the different pathways for PN/CT across the different disease areas and the way in which different healthcare systems influence the practice of PN/CT.

Through key informant interviews in the respective healthcare settings and organizations, the report highlights barriers, facilitators, tools and pathways of PN/CT as well as potential for integrating the four disease areas, ensuring that the pilot study effectively addresses key issues for each participating joint action partner. The interviews demonstrated a general confusion among interviewees in respect to PN/CT; not only on the official legal requirements and available guidelines, but also on how PN/CT is conducted on the ground. Specifically, there is confusion on which staff member has the responsibility to oversee and conduct PN/CT and concerns regarding the legality of conducting PN/CT services. This is often compounded by a lack of uniform set-up for partner notification across countries and healthcare systems. For example, in Ireland, each of the local departments of health acted independently, forming their own pathways and methods for partner notification. In Italy, some regions have created their own guidelines for partner notification, while others may utilize international guidelines or not specify any at all. An even more pressing barrier, noted unanimously, is a lack of resources and time to ensure that partner notification is handled appropriately and effectively.

Across sites and disease areas it was suggested that increased training on and awareness of partner notification and contact tracing could improve service outcomes. Healthcare workers need training on PN/CT, and the laws that surround it in their specific context, to feel confident in conducting these services and counselling patients on the topic. In Greece, a law (2472/1997) that protected patient confidentiality made healthcare workers feel less confident in what aspects of partner notification they were legally allowed to counsel and assist patients. This law has now been replaced by GDPR, resulting in similar effects. Across Europe, the advent of the GDPR in May 2018 has led to concerns related to patient confidentiality within the PN/CT process. In the instance that there are national or regional guidelines for PN/CT, often the healthcare workers that conduct PN/CT services do not have access to them or are not aware of them, rendering them ineffective. Clarification on the laws that surround the PN/CT process is needed. Despite the differences in healthcare contexts or disease areas, increased training on how to conduct PN/CT services could be applied to numerous settings, using country specific guidelines and information to guide the training.

Through interviews with key informants, it emerged that while HIV, STIs and in some instances viral hepatitis could be integrated without significant systemic changes, TB contact tracing is vastly different. In most settings, TB care and the contact tracing that accompanies it have pathways set in separate institutions from the other disease areas. While HIV, STIs and viral hepatitis are often within infectious diseases, TB tends to be housed in pneumology or public health. As the mode of transmission for TB is significantly different than that of the other disease areas, spreading through particles to close contacts, it follows that the contact tracing efforts for TB must be structured in a different method as well. This also affects the indicators that would be used to determine the effectiveness of PN/CT. While one list of indicators could work for HIV, STIs and potentially even hepatitis, these same indicators would not be applicable to TB.

For these reasons, it has been repeatedly noted that it would be difficult, and perhaps unwarranted, to try to integrate TB contact tracing into the partner notification efforts of the other disease areas. And while the differences are many, the interviews demonstrate that TB is typically the most developed PN/CT programme out of all the diseases, with a history of established pathways and national guidelines, offering the potential to learn from TB CT for other disease areas. Offering training for TB contact tracing may still be applicable to improve outcomes but finding one uniform method of partner notification/ contact tracing across the four disease areas is unlikely to affect change. While work continues to search for integration opportunities, this energy may be better served in drawing out learnings and lessons to move forward in other disease areas.

Monitoring PN/CT remains a challenge. Not only do confidentiality laws and requests for anonymity make it difficult to audit the effectiveness of PN, but also there are difficulties surrounding data protection with new GDPR requirements. Additionally, a national registry of PN/CT is not feasible in countries where there is no national registry of said disease. It is widely acknowledged that auditing PN/CT outcomes could improve resources and support for PN services, however it may not be within the scope of this project to address this issue.

A recurring barrier seen across sites and disease areas was a lack of time and resources to appropriately conduct partner notification and contact tracing. Regardless of the staff devoted to the task, it appears that the time-consuming nature of partner notification, as well as the high number of patients, results in a lack of adequate time to devote to PN/CT in the manner that is recommended. Several respondents noted that the use of community facilities or community based voluntary counselling and testing (CBVCT) centres for partner notification could be a potential option. Outsourcing the activity and increasing the number of staff available to assist the process could see positive results, if the staff involved with PN/CT were well trained. Additionally, using peers within PN services may be more acceptable to patients.

2.3 Repository of PN/CT Documents

There are no common EU/EEA guidelines on how to perform TB contact tracing or partner notification for HIV, STIs and viral hepatitis. Many member states have national guidelines for TB contact tracing, yet of those that do exist the criteria for selecting contacts, the screening process and the prescription of preventative treatment differs (European Centre for Disease Prevention and Control, 2012). International bodies, such as WHO, ECDC, IUSTI and more provide guidance on what should be included in national guidelines, but there is no standard European guideline for any of the four disease areas. As part of INTEGRATE WP7.2, partners collected all national contact tracing and partner notification guidelines for the selected disease areas as well as any laws that were applicable. These guidelines (or the specific section of these guidelines that were applicable) and laws were then translated to English, and both the original and the English versions were made available to the public on the INTEGRATE website for inspiration and reference².

Table 4: Country specific guidelines collected by Integrate*

Country	HIV/STIs	Viral Hepatitis	ТВ	
Croatia	No	No	Yes	

² Accessible at: <u>https://integrateja.eu/content/partner-notification-guidelines</u>

Integrate)
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Denmark	Yes	No	Yes			
Greece	No	Yes	Yes			
Hungary	Yes	No	Yes			
Ireland	No	Yes	Yes			
Italy	No	No	Yes- Regional			
Lithuania	Yes	No	Yes			
Poland	No	No	No			
Portugal	No	No	No			
Romania	No	No	Yes			
Serbia	Yes	Yes	Yes			
Slovakia	Yes	No	No			
UK	Yes	No	Yes			
Total	6/13	3/13	10/13			
*All guidelines are accessible at: https://integrateja.eu/content/partner-notification-guidelines						

2.4 Indicators

As previously discussed, it is not feasible to use the same indicators for PN/CT across all disease areas. Additionally, it is acknowledged that the gathering of indicators is heavily dependent on many regional and national practices and laws, as well as the healthcare systems and services. For example, in Italy PN services are often left to community health workers who do not have the ability to link in with national health systems to monitor data. Some healthcare workers also mentioned that when working with patients that are reluctant to disclose information on partners, gathering too many indicators could have the effect of dissuading them, and the benefits of gathering these outcomes should be weighed against the cost of potentially scaring off patients. For countries or regions that are interested in gathering more data on PN/CT services, the proposed indicators from Integrate partner CESSICAT include:

- % of index patients interviewed
- # of traceable partners per index patient
- # of partners contacted per index patient

In order to accurately demonstrate the effectiveness of PN, it is necessary to collect information on how many contacted partners are then screened, diagnosed and treated, but there are many practical and legal barriers to this. Data protection, patient confidentiality and a lack of connected monitoring systems make this unlikely. Two indicators which attempt to capture this information are:

- # of partners who agreed to attend screening and treatment
- # of patients who attend clinic because they were notified by a partner

While these are less precise and difficult to audit, they may help paint a better picture of the overall situation.

2.5 Integration Learnings and Difficulties

Some learnings point to modelling partner notification services for HIV, STIs and viral hepatitis after the wellestablished TB contact tracing pathways. The partner survey responses and mapping exercise indicated that TB contact tracing appears to be the most comprehensive and best resourced of all the disease areas. Many partners even identified national guidelines, documents or outlined the national procedures that are involved in contact tracing and demonstrating a certain level of awareness for contact tracing of TB. Recent literature also demonstrates that the majority of EU countries have a defined TB control structure with central management and/or national guidelines (Collin SM, 2018). Despite finding it difficult to integrate TB into the other disease areas, this level of awareness and understanding of CT could be used to model new approaches or advocacy for PN in other disease areas.

When investigating the integration of tuberculosis contact tracing with the other disease areas, it became clear that many countries examined had well established pathways for TB contact tracing. The history of TB in Europe led to significant resources and well-established protocols, many of which still remain today. In efforts to improve PN services in other disease areas, it is vital to examine the success of TB contact tracing services and draw on these examples rather than 'reinventing the wheel'. See Annex 2 for case studies on TB contact tracing pathways in Ireland and Romania.

3. Best practice

3.1 Training

As identified in the baseline survey and mapping exercise, there is a need for an upscale in training for partner notification. Historically, the UK has a well-established sexual health testing and treatment pathway. The British Association for Sexual Health and HIV (BASHH) Sexually Transmitted Infections Foundation (STIF) course was launched in the UK in 2002 as a competency-based training and assessment package for non-specialist and specialist healthcare workers. One module of the training focuses on partner notification and is used widely throughout the UK and Ireland as the main in-depth training that healthcare workers receive on partner notification. As identified by experts and included within the limited training programs available, such as the STIF course, there are a number of key components that must be covered in a training to ensure that healthcare and community health workers feel confident in their role. Topics covered in such a course should include different types of partner notification, look back periods, contraindications, local and national laws and guidelines, GDPR overview, tools for partner notification and techniques for motivational and non-judgemental interviewing.

3.1.1 INTEGRATE Training

Through Integrate WP 7.2 activities, training was identified as an area that needed improvement and INTEGRATE explored opportunities for piloting training programs. UCD's Dr. Lambert has worked with the BASHH STIF course for over a decade and is a certified course facilitator. After gaining approval by stakeholders, UCD obtained permission from the STI Foundation to use the STIF course materials in the INTEGRATE pilot project. In November 2018, partners from Italy and Greece, along with key identified stakeholders for each country, met to examine the STIF training curriculum and identify ways to modify the curriculum to fit the needs of the pilot countries.

In 2019, INTEGRATE partner LILA Milano expressed a desire to run the modified STIF training for their nationwide staff of community health workers. As the community health workers speak Italian, it was necessary to train two course facilitators who are fluent Italian speakers to teach the course. Dr. Lambert trained two individuals, one infectious disease physician and one civil-society worker, to teach the STIF course, ensuring that the materials were appropriate for the Italian context. All materials (videos, facilitator manual and presentations) were translated into Italian for use in the LILA Milano training. Overall, 31 community health workers were trained with positive feedback on the course. The active engagement from the participants demonstrates that the community health workers felt the training to be valuable. A 6-month post training survey could elicit further insights to the success of the training.

3.2 ICT Tools

The WHO (World Health Organization, 2016) and ECDC (European Centre for Disease Prevention and Control, 2013) note that there is no universally preferred or most effective method of partner notification. While some patients may prefer a personal conversation with their partners, others may find that healthcare assisted partner notification is an easier option. Additionally, there are some circumstances which may be more suited to anonymous PN/CT (for more information please see 'Key Populations'). Patients may also choose to avail of different methods for different partners, with some studies showing patients prefer healthcare assisted or provider referral for non-primary partners (World Health Organization, 2016).

There are a variety of existing tools that can be used to assist patients in notifying their partners, varying from traditional tools to ICT (information and communication technology) tools. Traditional tools include letter templates, contact slips and phone call scripts for patients to use as they tell partners (CDC, AIDSfree toolkit). Most organizations no longer use contact slips but having resources such as templates and scripts is still a valuable resource for patients.

There is an increasing number of ICT tools for use in notifying partners via text or email, with the option for the patients to remain anonymous. Of these ICT tools there are two main variations: 1) open access tools and 2) provider access tools. Open access tools may be used by any person at any time. Often, they allow the patient to choose a standard form letter to let the partner know that they have been in contact with someone who recently tested positive for an infection. The main concerns with open access tools surround misuse, that the tools may be used as a joke and not sent in earnest, however there is little to no research to indicate that this occurs. Some examples of open access tools include InSpot, Let Them Know and STD Check.

In an effort to avoid misuse of ICT tools for partner notification, some ICT tools require patients obtaining a login code from their healthcare provider in order to use the system. Once the patient has received a positive diagnosis the healthcare provider will give the patient a code which allows them to login to the tool and send messages to their partners. The provider-controlled access tools can limit the number of partners a patient may notify, designate a length of time that the code will remain active and may also identify only specific infections. Additionally, some tools must be used on the premises where the patient is diagnosed while others allow patients to access the ICT portal from

a mobile or a personal computer. Examples of provider access tools include Partner Alert, Partner Waarschuwing, Checkpoint LX and SXT. The SXT tool has additional features, allowing the partner to opt out of receiving a text and a feature helps to link the partner to care. The text that the partner receives will include a link to identify their nearest testing facility and allow them expediated access for an STI screening with their unique identifier code.

A descriptive list of the tools mentioned above may be found in Annex 3.

3.2.1 INTEGRATE tool

A separate component of INTEGRATE was creating the RiskRadar, an integrated ICT tool for the four disease areas, with a partner notification component included. In order to overcome security challenges that exist in some available ICT PN tools, INTEGRATE designed a new tool to complement current practices of notifying partners of patients diagnosed with STIs.

The RiskRadar partner notification tool includes the following technical features to ensure security compliance: a) a user interface dedicated to healthcare professionals that can be accessed through a double-authentication mechanism, b) a user interface dedicated to patients that can be accessed only by a code and c) an SMS mechanism that is fully anonymized and GDPR compliant. Each code is generated by professionals and is delivered to the patient together with the diagnosis. The code is encrypted and can be used for a limited timeframe. Every time a misuse is identified by the system, the professional is notified to deactivate the code. Finally, the service is free of charge.

Unfortunately, due to delays and the impact of the spread of the Corona Virus across Europe, the partner notification tool had not yet been piloted properly.

3.3 Guidelines

3.3.1 SOP creation

As identified in the partner survey and the mapping exercise (MS38), there is general confusion surrounding the national laws and guidelines for contract tracing (CT) and partner notification (PN) for TB, HIV, STIs and viral hepatitis. Once these were identified, it was decided to create a standard operating procedure (SOP) for the CT/PN protocols for Italy and Greece, integrating the four disease areas into one document for ease of use by healthcare and community health workers.

Utilising international best practice guidance, particularly the International Union Against Sexually Transmitted Infections (IUSTI) template (Tiplica GS, 2015), members from UCD, EODY, LILA Milano and country experts in CT/PN met in Milan to discuss the different CT/PN pathways for the four disease areas. These pathways were then combined into one document with visual aids to be used and amended by each partner within their country. The finalized SOPs include indications and contraindications for PN, the procedure and pathway for PN by disease area, an overview of any legal requirements (national regulations, patient protections, GDPR), tools for use by healthcare and community health workers, management of contacts and monitoring and one-page flowcharts for pathways for ease of use.

From early investigations, it was clear that integrating TB CT with the PN of the other disease areas was difficult and unwarranted, given the different modes of transmission and public health considerations. However, it was still possible to create one document that included the SOP for each disease area. In Italy, there was the additional challenge that each region's health system is independent from the other, and so it was decided that the SOP created would be specific to the Lombardi region, but could also serve as a template and an example for other regions in the country. In Greece NPHO/EODY is the sole body responsible for planning and promoting protection and awareness-

raising actions, with particular focus on public health services such as CT/PN. Unfortunately, there were many organizational changes in EODY during INTEGRATE, which led to delays.

The SOPs which were created are intended for use in Greece and Italy, as well as an example template for other countries that are interested in creating a national or regional SOP to standardize CT/PN. While each country already had national guidance on TB CT, healthcare providers expressed an interested in a clear description of the PN protocol. These SOPs may be tailored to different regions, used in training of new personnel, or as a resource in the future. The template is easily customisable and INTEGRATE encourages each partner (and other interested parties) to take these documents and modify them to suit their own country/ region.

The SOP describes the official pathway for CT/PN of the four disease areas, yet it is important to remember that the reality of the CT/PN process may be significantly different 'on the ground'. As with other national guidelines, the key to the success of the SOP is that those performing the responsibilities every day are aware of the document in order for it to be of any assistance to them, so it is suggested that the SOP launch is accompanied by a dissemination strategy. The dissemination strategy could be in line with a national meeting promoting partner notification, discussed in healthcare and community healthcare worker trainings or in line with the creation or update of a national guideline for a disease area. Additionally, these SOPs must be coupled with training on PN to ensure that healthcare and community health to use the SOP.

A template for creating an integrated SOP can be found in Annex 4.

3.4 Key Populations

Partner notification interventions typically focus on the heterosexual and MSM populations, leaving a crucial gap in knowledge for specific vulnerable populations. One aim of INTEGRATE was to identify partner notification/ contact tracing methods suitable for key vulnerable populations, including PWID, prisoners, migrants/refugees and sex workers. Originally, INTEGRATE aimed investigate appropriate strategies for vulnerable populations in a pilot project, utilizing the ICT tool and focus groups to gain insights into how PN/CT interventions should be tailored to the different populations. Unfortunately, at the time of writing this report, the pilot on this ICT tool is yet to begin due to a series of complications and delays. Additionally, there is little to no information in published literature on targeted PN/CT interventions for these key populations. Here is a brief overview of the scant literature on the topic.

As noted by Katz et al, there are concerns that PN/CT services will not be acceptable to key populations, however literature is beginning to surface that suggests potential practices are acceptable (Katz DA, 2019). A 2019 study from Vietnam targeted key populations through assisted PN/CT services as part of a community-led peer-educator based program (Nguyen VTT, 2019). The study accessed MSM, PWID, partners of PLHIV and sex workers by utilzing a peer worker led program with a number of different approaches for different key populations. These methods include: face-to-face outreach and small group discussions through existing networks for PWIDs, social media networks and dating apps for MSM, offering self-testing and lay-provider testing for those reached by assisted PN and choosing peers from key population groups. In Pakistan a study focused on reaching spouses of PWID through field outreach and sensitization of wider family members in order to overcome cultural barriers (Malik M, 2019). Specifically, the outreach workers worked with members of the joint family system who lived in the same household to reduce stigma and demonstrate the need for partner testing. In Uganda a study focused on fishermen and sex workers found provider referral, which helped patients remain anonymous, to be the most suitable for motivating PN with multiple casual partners in contrast to findings on the general population where patient referral was often preferred (Quinn C, 2018). In all studies, contacting casual partners remains a key barrier to PN/CT for a variety of reasons.

Noting the difficulties in utilizing traditional approaches to PN/CT, there is a new trend emerging in the field of risk network-based approaches to targeted testing, which appears to be more suitable for the PWID population. Studies have shown respondent-driven sampling (RDS) and peer based active case finding (ACF) to be useful tools for targeting sexual and needle sharing partners. These programs use initial recruits called "seeds" utilizing incentives and coupons to bring in partners from their risk networks. These network-based methods are suggested to be used alongside other traditional partner notification methods in order to access the hard-to-reach populations (Kan M, 2018) (Smyrnov P, 2018). In one study, RDS resulted in proportions testing HIV positive between 1.5-2.6% with 68.3% responding as first-time testers, while ACF yields were 1.5% with 85.1% identifying as first-time testers (Kan M, 2018). Active case finding has also been used in developing countries to target key populations for TB screenings, resulting in improved yields (Karamagi, 2018).

Contact tracing within migrant communities is a significant concern. A study with immigrants in Barcelona suggested that TB contact tracing efforts with immigrants can be improved by incorporating community health workers who act as translators, cultural mediators and facilitators, accompanying cases and contacts through treatment and follow up (Ospina JE, 2012). The Ospina study saw contact tracing performed on 81.6% of smear-positive cases during the intervention period compared with 65.7% during the pre-intervention period (2012). As TB contact tracing is traditionally carried out by public health or respiratory facilities, this would result in a significant change in protocol. A 2015 study in Istanbul also highlighted the potential for improving TB contact tracing efforts among migrants by utilizing community-based interventions (Yasin Y, 2015).

Conducting partner notification services in prisons presents additional challenges. With patients in close confines and overcrowding, extra precautions must be taken to ensure that eliciting information about partners is done in a private setting and does not draw additional attention to the prisoner. For this reason, it is suggested that this is done in posttest counselling or at a patients regularly scheduled clinic to avoid patients being singled out. As opportunities for patient referral are limited, provider referral may be more heavily relied on in prison settings. Separating those who attend patients in a prison clinic from those who contact partners is suggested to assist in maintaining the patients' anonymity, encouraging the use of community health workers to perform such tasks. Additionally, literature highlights that any information that would allude to the incarceration of the patient should not be dispensed, as this may be sufficient to identify the patient (Culbert GJ, 2019).

4. Legal

As mentioned previously, the legal environment surrounding partner notification varies greatly from country to country (Power L, 2018), creating a significant barrier for cross-border training programs and guidelines. As demonstrated in the ECDC report (European Centre for Disease Prevention and Control, 2013), some countries make partner notification mandatory, while others have no requirements to engage in partner service; some allow healthcare providers to assist patients in notifying partners while others only allow patient referral. This variation can be a source of great concern to healthcare providers to support patients in partner notification, it is important that they understand the applicable national laws, and so it is recommended that all training efforts include information on the local laws, rights and restrictions as they apply to PN/CT services. When compiling the repository of national guidelines and documents, INTEGRATE also collected information on any laws that were applicable to PN/CT.³

³ These can be accessed at <u>https://integrateja.eu/content/partner-notification-guidelines</u>.

While a number of countries do not have specific laws that prohibit or mandate PN, some have conflicting laws. For example, Hungary has a law that requires patients to give information on their partners for specific STIs, yet these efforts are in conflict with laws that protect patient confidentiality and anonymity. In Greece and Italy, patient confidentiality laws protect against mandatory or involuntary PN, yet there are provisions for a doctor to seek permission to disclose a patient's status against their will in rare cases.

Country	Laws or Regulations related to PN/CT*
Croatia	Legislation on PN for HIV, STIs and viral hepatitis. Patient confidentiality law.
Denmark	No laws that prohibit or mandate PN.
Greece	Patient confidentiality law- protects against mandatory or involuntary PN
Hungary	Law requiring patients to provide contacts for specific STIs. Patient confidentiality and anonymity law.
Ireland	No laws that prohibit or mandate PN. Patient confidentiality laws.
Italy	Patient confidentiality law- doctors must obtain permissions to disclose without permission.
Lithuania	No laws that prohibit or mandate PN.
Poland	No laws that prohibit or mandate PN.
Portugal	-
Romania	-
Serbia	Patient confidentiality law. Criminalization of HIV transmission.
Slovakia	HIV disclosure mandated by law.
υк	No laws that prohibit or mandate PN.
Total	6/13
*All collected legal guidelines	documents may be found at: <u>https://integrateja.eu/content/partner-notification-</u>

Table 5: Country specific lega	I requirements related to PN/CT.
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Throughout INTEGRATE, two legal areas of specific concern were identified: the criminalization of HIV transmission and the advent of GDPR.

4.1 Criminalization

Despite the effectiveness of PN/CT in finding new infections, some countries still have laws which act as a barrier to the process, by criminalizing transmission of disease and increasing stigma (Power L, 2018). When discussing the potential adverse outcomes of partner notification, it is important to highlight that partner notification is not

mandatory and should always be considered in light of each patient's situation (as noted by WHO, UNAIDS, ECDC, IUSTI, etc). Partner notification should be supported as a voluntary process, ensuring the patient's safety.

A main barrier to partner notification remains the criminalization of HIV transmission and non-disclosure in some countries (M, 2019). In order to encourage the safety of patients and reduce the stigma associated with the disease, it is crucial to repeal laws that criminalize the conduct of PLHIV. The HIV Justice Network and the GNP+ Global Criminalisation Scan⁴ maintains an updated list of criminal laws used to regulate PLHIV as well as all criminal HIV cases around the world. Studies note the importance of weighing the benefits of partner notification against the costs, particularly in cases where patients may be criminalized or subjected to violence (Ayala G, 2019).

4.2 General Data Protection Regulation

The General Data Protection Regulation (GDPR) 2016/679 regulates data protection and privacy in the EU and EEA⁵. GDPR was implemented on 25 May, 2018, within the first year of Integrate, and it was immediately clear that the implications of GDPR on PN/CT services must be addressed, as healthcare providers and community health workers expressed concerns on the legality of performing of PN services within the new regulation. Below is a brief overview of GDPR as it relates to partner notification.

Under GDPR, Article 9,1 "Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited."

Article 9,1 shall not apply if one of the following applies: ...9,2 (i) "processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy;"

Article 9, 2 (i) provides a clear provision to allow the continued practice of partner notification for reasons of public health interest if utilizing safeguards to the data subject. In countries that allow healthcare assisted partner notification, this provision expressly provides them the ability to engage in partner notification. In countries where patient referral is the only method of partner notification supported through legislation, GDPR is <u>not a concern</u>, as patient referral does not involve the healthcare worker sharing any personal data. However, INTEGRATE has demonstrated a clear need to clarify these points with the healthcare and community health workers who perform PN services, as many cited these concerns as preventing them from carrying out their work. It is crucial that any training on PN/CT cover GDPR in order to alleviate any fears healthcare providers or community health workers may have. At the time of writing there were no studies which discussed or analysed the effects of GDPR on PN services.

⁴ <u>http://criminalisation.gnpplus.net/</u>. Accessed on April 20th, 2020.

⁵The entire GDPR regulation can be accessed at: <u>https://gdpr-info.eu/</u>.

5. Limitations and Gaps

The joint action allowed INTEGRATE to collaborate with a number of stakeholders across a number of countries and healthcare settings. This was a significant asset, however, there remain a number of limitations faced by the joint action which would benefit from further study. Planned pilots were refocused due to information received from INTEGRATE partners within year one of the joint action. Following this, one of the pilot countries (Romania) withdrew from the study. Additionally, delays in the creation of the ICT tool, coupled with the onset of COVID-19 resulted in the inability to pilot the INTEGRATE PN tool within key populations. Therefore, it remains to be seen if ICT tools are acceptable and/or used by these key populations.

To demonstrate effectiveness and ensure partners are being 'captured' through PN/CT services, there is a need for systems which monitor partner notification at a regional or national level. While individual clinics often have a method for tracking partners, there is a need for wider systems to more accurately capture data on partner notification and account for partner mobility. There are many barriers to this, including a variety of systems in use, lack of IT infrastructure, data protection and patient and partner mobility and anonymity.

The advent of GDPR regulations at the beginning of this project created a significant concern for healthcare providers and community health workers providing PN services. INTEGRATE saw a significant delay in participation as organizations grappled with compiling with GDPR. It requires further research to see if GDPR had the effect of restricting partner notification and how those providing PN services have changed practices, if applicable.

6. Conclusions and recommendations

In conclusion a list of proposed recommendations for improving uptake and effectiveness of partner notification practices have come from the work in WP7.2. The recommendations have been separated by target audience, although some cut across multiple stakeholders. This list is not exhaustive and should be used as a starting point rather than a definitive compilation.

Policy Makers:

- Support and create national guidelines for partner notification, integrated where possible. Possible to take inspiration from established TB pathways and structures.
- Support partner notification as a necessary prevention and elimination practice, dedicating more time and resources for partner notification processes and raising awareness of the benefits of partner notification.
- Decriminalize transmission of disease and clarify rights of healthcare workers to assist with partner notification services.

Clinicians/ Healthcare Staff:

- Improve training on partner notification for those involved in PN services. Trainings should address: techniques, tools, contraindications, local and regional guidelines, local and national laws and regulations surrounding PN, resources for patients and healthcare workers, appropriate referral information and practical examples.
- Create standard operating procedures for partner notification, easily accessible for healthcare and community health worker staff. SOPs should integrate disease areas where possible and include quick reference infographics, information on official and non-official pathways and appropriate links and phone numbers.
- Partner notification needs improved monitoring systems and indicators across regions and disease areas in order to accurately capture PN data and effectiveness.

Civil Society Organizations:

- Raise awareness on the benefits of partner notification, as well as the different methods and services that can be utilized for PN.
- Promote CSOs and peer services as additional outlet for PN services for overburdened health systems.

Research:

- How did the advent of GDPR in 2017 affect partner notification practices? Many organizations remain confused about how GDPR affects their ability to practice and promote partner notification, leading to a potential decline in PN services.
- The acceptability of ICT tools for partner notification within key populations is unknown. Research is needed to understand how tools can be promoted, accepted and made effective for migrants, sex workers, prisoners and PWID.

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Abbreviations

WHO - World Health Organisation

Appendix A. Integrate Baseline Survey Results

Table 1: Is PN/CT mandatory in your country?

Country	Organization type	HIV	Нер В	Hep C	Syph	Chla	Gonorr	тв
Ireland	University	No	No	No	No	No	No	yes
Italy	NGO	No	No	No	No	No	No	Yes
Italy	NGO	No	No	No	No	No	No	No
Poland	Public Health	No	No	No	No	No	No	No
Poland	University	No	No	No	Yes	No	No	No
Croatia	NGO	No	No	No	No	No	No	No
Croatia	Public Health	Yes	Yes	Yes	Yes	-	-	Yes
Croatia	NGO	No	No	No	No	No	No	-
Croatia	NGO	No	-	-	-	-	-	-
Slovakia	University	No	Yes	Yes	Yes	Yes	Yes	Yes
Hungary	University	No	-	-	Yes	No	Yes	-
Hungary	Public Health	Yes	Yes	No	Yes	Yes	Yes	yes
Lithuania	Hospital	No	No	No	No	No	No	-
Lithuania	Hospital	Yes			Yes	Yes	Yes	Yes
Lithuania	Public Health	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lithuania	Public Health	No	No	No	No	No	No	No
Spain	Public Health	No	-	-	-	-	-	Yes
Malta	Public Health	Yes	Yes	Yes	Yes	Yes	Yes	-
Romania	Hospital	Yes	-	-	-	-	-	Yes
Romania	Hospital	Yes	-	-	-	-	-	Yes
Slovenia	Public Health	No	No	No	No	No	No	Yes
Estonia	Public Health Research	Yes	Yes	Yes	Yes	No	No	Yes
Greece	Public Health	-	-	-	-	-	-	-
Greece	Research Institute	-	-	-	-	-	-	-
Serbia	Public Health	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Portugal	NGO	No	No	No	No	No	No	Yes
Norway	Public Health	-	-	-	-	-	-	-
Reported mandatory		9/27	7/27	6/27	10/27	5/27	7/27	14/27

Country	Organization type	HIV	Нер В	Hep C	Syph	Chla	Gonorr	ТВ
Ireland	University	No	No	No	No	No	No	Yes
Italy	NGO	No	No	No	No	No	No	No
Italy	NGO	No	No	-	Yes	No	No	No
Poland	Public Health	No	No	No	No	No	No	No
Poland	University	No	No	No	No	No	No	-
Croatia	NGO	-	-	-	-	-	-	-
Croatia	Public Health	No	No	No	No	No	No	No
Croatia	NGO	No	Yes	Yes	Yes	Yes	Yes	Yes
Croatia	NGO	No	-	-	Yes	-	Yes	-
Slovakia	University	Yes	Yes	No	Yes	Yes	Yes	Yes
Hungary	University	No	No	No	No	No	No	No
Hungary	Public Health	Yes	-	-	Yes	Yes	Yes	Yes
Lithuania	Hospital	No	No	No	No	No	No	No
Lithuania	Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lithuania	Public Health	Yes	-	-	-	-	-	Yes
Lithuania	Public Health	Yes	-	-	-	-	-	Yes
Spain	Public Health	No	No	No	No	No	No	Yes
Malta	Public Health	-	-	-	-	-	-	-
Romania	Hospital	No	No	No	No	No	No	No
Romania	Hospital	No	No	No	No	No	No	No
Slovenia	Public Health	No	No	No	No	No	No	-
Estonia	Public Health Research	Yes	Yes	Yes	-	-	-	Yes
Greece	Public Health	No	No	No	No	No	No	No
Greece	Research Institute	-	-	-	-	-	-	-
Serbia	Public Health	No	No	No	No	No	No	No
Portugal	NGO	-	-	-	-	-	-	-
Norway	Public Health	-	-	-	-	-	-	-
Legally required reporting		6/27	4/27	3/27	6/27	4/27	5/27	9/27

Table 3: Are there any	guidelines for	PN/CT in your	country?
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Country	Organization type	HIV	Нер В	Hep C	Syph	Chla	Gonorr	ТВ
Ireland	University	No	No	No	No	No	No	Yes
Italy	NGO	No	No	No	No	No	No	No
Italy	NGO	No	No	-	Yes	No	No	No
Poland	Public Health	No	No	No	No	No	No	No
Poland	University	No	No	No	No	No	No	-
Croatia	NGO	-	-	-	-	-	-	-
Croatia	Public Health	No	No	No	No	No	No	No
Croatia	NGO	No	Yes	Yes	Yes	Yes	Yes	Yes
Croatia	NGO	No	-	-	Yes	-	Yes	-
Slovakia	University	Yes	Yes	No	Yes	Yes	Yes	Yes
Hungary	University	No	No	No	No	No	No	No
Hungary	Public Health	Yes	-	-	Yes	Yes	Yes	Yes
Lithuania	Hospital	No	No	No	No	No	No	No
Lithuania	Hospital	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Lithuania	Public Health	Yes	-	-	-	-	-	Yes
Lithuania	Public Health	Yes	-	-	-	-	-	Yes
Spain	Public Health	No	No	No	No	No	No	Yes
Malta	Public Health	-	-	-	-	-	-	-
Romania	Hospital	No	No	No	No	No	No	No
Romania	Hospital	No	No	No	No	No	No	No
Slovenia	Public Health	No	No	No	No	No	No	-
Estonia	Public Health Research	Yes	Yes	Yes	4	-	-	Yes
Greece	Public Health	No	No	No	No	No	No	No
Greece	Research Institute	,	4	-	4	-	-	-
Serbia	Public Health	No	No	No	No	No	No	No
Portugal	NGO	-	-	-	-	-	-	-
Norway	Public Health	-	-	-	-	-	-	-
Legally required reporting		6/27	4/27	3/27	6/27	4/27	5/27	9/27

Appendix B: Country Case Studies

2.1 TB Case Study Ireland

Ireland's last guidelines on TB were published in 2010 yet there remains no national control plan, nor is that there an established clinical program for TB contact tracing. Instead, Ireland's historical health department infrastructure remains a key feature as to the organization of TB contact tracing, with each local department of health managing the TB cases in their region. However, there are similarities in the process as it is completed.

Reporting of suspected or confirmed cases of TB is the responsibility of the treating or diagnosing clinician as well as the laboratory that confirms the positive result. Notifications are then made to the local department of health by telephone or secure email, where a clerical officer receives the information. The clerical officer then contacts the public health physician covering the relevant geographic area, and from this point on the responsibility of contact tracing remains with public health.

All cases of TB in Ireland are reported on the Computerized Infectious Disease Reporting (CIDR) system, which also compiles TB treatment outcome data annually. Additionally, the Irish Mycobacteria Reference Laboratory (<u>http://www.stjames.ie/Departments/DepartmentsA-Z/I/IMRL/DepartmentOverview/</u>) provides genotyping of TB specimens which can be useful for epidemiological and contact tracing purposes. However, there is no national ICT surveillance system for TB contacts or contact tracing efforts. The department of public health remains responsible for contact tracing, and each local department methods will differ slightly based on resources.

In the East of the country, the area that sees over half of all TB cases in the country, contact tracing is carried out by public health doctors. Briefly the contact tracing process involves:

- Contacting the lab to confirm the diagnosis
- Contacting the index case's clinician to obtain any relevant information
- Interviewing the index case by telephone or in person to determine who had significant contact with them during the presumed infectious period. (see <u>https://www.hpsc.ie/a-</u> <u>z/vaccinepreventable/tuberculosistb/guidance/tbguidelines2010amended2014/File,4349,en.pdf</u>)
- Details of the index case, their contacts and results of their screening are recorded on a contact tracing record (Microsoft Word file)
- These are stored securely in a folder on the Department of Public Health East server. Access to this folder is restricted to the members of the local TB contact tracing team
- Contacts are then contacted by phone/letter to offer them an appointment for screening at a contact tracing clinic.
- Contacts attend for screening at a hospital clinic and notes are recorded in a hospital chart (paper or electronic depending on the particular hospital) in the normal way

The main barriers in Ireland remain that there is no dedicated funding for contact tracing, language difficulties within the migrant communities and the difficulty in following up a highly mobile migrant community. An ICT surveillance system for contacts would certainly be useful and perhaps the COVID tracker system could be used as a model for this. Additional nurses to assist with the contact tracing procedures would also be beneficial.

2.2 TB Case Study Romania

Romania's TB contact tracing is conducted in accordance with Guidelines for the Implementation of the National Program for the Prevention, Surveillance and Control of Tuberculosis (NTP) approved in 2015.

TB detection can be performed both by primary care doctors (general practitioners or family doctors) and by other specialists. Cases are reported within 48 hours by the doctor who diagnosed the case or initiated the TB treatment through the Case Announcement Form addressed to the Pneumophthisiology/TB Dispensary (TBD) according to the place of residence. All TB cases are recorded in the chronological order in the TBD TB Registry and in the national electronic database.

Contact tracing must be triggered at the suspicion of any TB case, within a maximum 72 hours, by the pulmonologist from the TB Dispensary in whose territorial area the case/outbreak occurred. The contact tracing responsibilities are allocated as follows:

- The pulmonologist in the TB Ambulatory a) initiates the contact tracing, organizes and participates directly whenever necessary in the application of prophylactic and anti-epidemic measures in the outbreak (identification of the index case); b) performs (together with the family doctor / school/ occupational medicine specialist) the contact tracing for TB cases, ensuring the examination of contacts (clinical examination, TST, radiological, bacteriological), c) is responsible for the quality of the contact tracing and its completion; d) reports the outbreaks (with more than 3 confirmed cases) from schools/work communities to County Public Health Department/ Epidemiology Department of the Bucharest Municipality.
- Family doctor, school doctor or occupational medicine specialist a) effectively participate in the contact tracing in the territory where the person suspected of having TB resides or works, by identifying all the contacts and referring them to specialized investigations after performing the clinical examination; b) applies the measures indicated by the pulmonologist from TBD (prophylactic treatment); c) carries out health education of the patients with tuberculosis and their families.
- The epidemiologist: a) coordinates the contact tracing in outbreaks with at least 3 cases; b) reports the outbreaks to the National Institute of Public Health Center for National Center for Surveillance and Control of Communicable Diseases; c) collaborates with the pneumophthisiology/TB network for the training the medical staff in the application of the TB control program provisions; d) monitors the development of the TB program at county level, in collaboration with the TB county coordinating doctor and proposes, if necessary, additional measures of surveillance and control of the outbreak.

Data on contact tracing is fragmented at county and dispensary levels, there is no centralized data point on contacts screened. For an annual report, the data should be requested and collected in a separate activity as it is not regularly collected. The patient is asked to inform his contacts about the possibility of having contracted the disease but they very rarely do, that is why there are other mechanisms in place to screen the contacts and in most cases the health professionals are the ones doing it.

Appendix C: Matrix of ICT Tools for PN

Partner Notification Tools and Descriptions

Source	Name	Description	Type of Tool	Availability	Disease Areas	Results of Use (if available)	Link
CheckOUT (via	CheckOut	PN portal accessible to	Partner	Private	HIV, STIs	From 2015 to 2018, 897 logins given to patients, 90 logins used	https://www.checkpointlx.com/checkpointlx
CheckpointLX)		clients of the checkpoint	Notification			with 516 SMS and 20 emails sent total. Total notification costs	
		through a login given by	Portal			€15. 50 MSM reported taking rapid test due to receiving	
		the service. After clients				anonymous notification, with 2 HIV and 4 syphilis cases	
		input partners' contact #				detected. 15 MSM reported scheduling STI appointment due to	
		or emails, system				receiving anonymous notification with 1 chlamydia detected.	
		automatically messages				(Results presented at HepHIV 2019. Contribution of	
		partners, without				anonymous partner notification service on	
		requesting any I.D. data of				HIV/sexual transmitted infection (STI) detection at	
		pts and automatically				a community-based sexual health centre for men who have sex	
		deletes partner info after				with men (MSM). Rocha, M. Bucharest, Romania)	
		messages are sent					
UK source	SXT	Uses ID numbers and an	Website,	Private	HIV, STIs	Between 01/12/17-31/07/18, 6414 index cases initiated PN via	https://sxt.org.uk/pn/about
		online platform that	IDCS			SXT across 13 sexual health providers. The number of verified	
		allows for multiple	(interactive			tested partners per diagnosis via SXT vs. national data were	
		methods of informing	digital			higher for CT, GC and STS. Based on known STI prevalence in	
		partners without storing	contact			partners, a predicted 133 GC, 77 CT and 12 STS additional	
		any index patient	slip)			diagnoses were made using SXT during the 7 month period.	
		information				(Presented at CROI 2019, Seattle, Washington.	
						https://www.croiconference.org/abstract/partner-notification-	
						increasing-effectiveness-modern-communication-technology/)	



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SOAAIDS	Man to Man	Partner notification website	Mobile application	Public	HIV, STIs	-	https://mantotman.nl/en/contact
	So They Can Know	A website that allows users to view tips, scripts, and videos about how to notify their partners, or send anonymous partner notification emails. These emails provide partners with relevant health information and links to locate nearby testing services. Link no longer active	Dedicated Website	Public	HIV, STIS	During an unknown period, the website reported had 9,735 unique visitors. Of these, 706 people looked up information about how to tell their partners themselves, and 270 anonymous notification emails were sent. (https://www.changemakers.com/rwifopen/ideas/entries/so- they-can-know-std-partner-notification-website)	https://sotheycanknow.splashthat.com/
Melbourne Sexual Health Centre	Let Them Know	Website with FAQs for partner notification and examples of conversations, emails, text messages (SMS) or letters you can use in informing your partner with online SMS or email options, either personally or anonymously, and the option to ask healthcare providers for assistance	Dedicated Website	Public	STIS	During an 11-month period, the site was visited 6,481 times (5,785 new users), which resulted in 2,727 text messages and 108 e-mail messages being sent to partners. (Huffam S, Fairley CK, Chung M, Sze JK, Bilardi J, Chen MY. Facilitating partner notification through an online messaging service: Let Them Know. Sexual Health. 2013;10(4):377–379. doi: 10.1071/SH13007.)	https://letthemknow.org.au/



Buckley	Don't Spread It	Website that allows you to	Dedicated	Public	HIV, STIs	-	https://www.dontspreadit.com/
Innovations,		send anonymous email or	Website				
LLC		text message to tell					
		partners that they have					
		been exposed to STI.					
		Partners receive a code					
		that they use to sign in and					
		retrieve their message,					
		and have the opportunity					
		to respond to the sender.					
		Stand alone tool that					
		allows partners to send					
		messages back to senders					
		if desired.					
Internet	inSPOT	A peer-to-peer, Web-	Online	Public	HIV, STIs,	Launched in 2004, by 2008 more than 30,000 people had sent	https://inspot.org/TellThem/tabid/58/language/en-
Sexuality		based, STD partner	Resource		viral	over 49,500 e-cards, with fewer than 10 recipients reporting	US/Default.aspx
Information		notification system that			hepatitis	receiving one in error. From December 2005 through February	
Services, non-		uses electronic postcards			-	2008, 29,137 people accessed STD testing information as a result	
profit		(e-cards) to assist people				of receiving an e-card.	
		in disclosing an STD				(https://doi.org/10.1371/journal.pmed.0050213)	
		diagnosis to their sex					
		partner(s). Link no longer					
		running.					
	Partner Alert	Provider access based	Dedicated	Private	HIV, STIs	-	https://www.partneralert.be/
		partner notification	website				
		website					
	Partner	Provider access based	Dedicated	Private	HIV, STIs	-	https://partnerwaarschuwing.nl/
	Waarschuwing	partner notification	website				
	_	website					
	STD Check	Anonymous text or email	Dedicated	Public	Open-	-	https://www.stdcheck.com/anonymous-
		with form message. Open	website		intended		notification.php
		to public			for STIs		



USAID	AIDSFree	A knowledge base for	Online	Public	Open-	N/A	https://aidsfree.usaid.gov/resources/hts-
		partner notification tools	resource		intended		kb/assisted-partner-notification/tools-and-curricula
		and curriculum available			for STIs		
		for download					
CDC	IPS Toolkit	A toolkit for introducing	Online	Public	Open-	N/A	https://www.cdc.gov/std/program/ips/IPS-Toolkit-
		technology into partner	resource		intended		<u>12-28-2015.pdf</u>
		services available for			for STIs		
		download					

Appendix D: Integrated PN/CT SOP Template





(Country Name) Partner Services: Standard Operating Procedure

November 2018



Co-funded by the Health Programme of the European Union Co-funded by the 3rd Health Programme of the European Union under Grant Agreement nº 761319

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2. Introduction

3. Purpose

This document describes the standard procedure for partner notification/ contact tracing services in (<u>country</u>).

The guidelines and recommendations in this manual are not intended to be set in stone. They are designed to be updated and expanded on as necessary and as changes in medical practice and legislation arise.

4. Background

WHO notes that partner notification is an important public health approach in infectious disease management. Partner notification has clinical benefits – it aims to prevent re-infection of the index patient and treat their sexual and needle-injecting partners and close contacts – as well as public health benefits – it aims to control the spread of infectious diseases and reduce infectious disease related morbidity and mortality. It is also a key strategy for reaching infected people who are asymptomatic and people who do not present for diagnosis, counselling and treatment. There are different approaches to partner notification, which can be broadly defined as patient referral, provider referral, and contract or conditional referral.

Assisted partner notification has been an important public health approach in infectious disease management for decades, including in programmes targeting sexually transmitted infections (STIs) and tuberculosis (TB). STI partner notification approaches have been shown to be effective in diagnosing and treating STIs and preventing recurrent infection. Likewise, active tracing of contacts and the voluntary screening of household members of people with active TB is an effective and standard approach that has been used successfully in communities with high HIV and TB prevalence.

5. Definitions

Partner notification, or disclosure, or contact tracing, is defined as a voluntary process whereby a trained provider asks people diagnosed with an infectious disease about their sexual partners and/or drug injecting partners and then, if the diagnosed patient agrees, offers these partners HTS. Partner notification is provided using passive or assisted approaches (WHO, 2015). In this manual, partner notification will be used in place of contact tracing, even though in some disease areas this will refer to contacting individuals that are not 'partners' of the index patient.

Passive partner notification services refer to when diagnosed patients are encouraged by a trained provider to disclose their status to their sexual and/ or drug injecting partners by themselves, and to also suggest HTS to the partner(s) given their potential exposure to infection.

Assisted partner notification services refer to when consenting diagnosed patients are assisted by a trained provider to disclose their status or to anonymously notify their sexual and/or drug injecting partner(s) of their potential exposure to infection. The provider then offers testing to these partner(s). Assisted partner notification is done using contract referral, provider referral or dual referral approaches.

Provider referral: With the consent of the infected patient, a trained provider confidentially contacts the person's partner(s) directly and offers the partner(s) voluntary HTS. In many countries, this is only permissible after the involvement of legal or public health committees. Annex A

6. Indications for PN

7. Timing of PN

According to the WHO, partner notification services should be offered as part of a comprehensive package of testing and care. While patients should promptly be offered voluntary partner services, it is important to remember that a patient may not be ready to disclose their status upon receiving the diagnosis. For this reason, patients should be offered partner services throughout their interaction with the health system, from diagnosis, to enrolment in treatment, and any follow up visits (WHO, 2016).

8. Look-back Intervals By Disease

The appropriate look-back interval for partner services should be used. The look-back interval is the time during which the index case may have been infectious and transmitted infection, and should be applied to all contacts whether or not protection was used. The table below lists the infections for which PN should be offered contact actions agreed with the index case, and followed up by a HCW with the appropriate documented competency (Annex B). The corresponding look-back intervals, and whether or not epidemiological treatment of contacts is recommended, is also given. However, these look-back intervals are for guidance. Every case should be assessed on the basis of the sexual history, risk assessment and particular

circumstances. There may be benefit in offering PN for some contacts outside these look-back intervals, and justification for not offering PN within the specified intervals.

9. Contraindications

While partner notification is an important prevention method, there may be situations in which it is not safe for a patient to disclose to their partners. If the patient has any concerns of violence, healthcare workers should utilise the intimate partner violence (IPV) screening tool to help assess if partner notification should proceed (Annex C).

10. IPV assessment:

With the patient, the healthcare worker/ designated staff member should review any partners where there is a risk or concern of violence. The screening for intimate partner violence includes four questions:

- 1. Has [partner's name] ever hit, kicked, slapper or otherwise physically hurt you?
- 2. Has [partner's name] ever threatened to hurt you?
- 3. Has [partner's name] ever forced you to do something sexually that made you uncomfortable?
- 4. Do/ did you generally feel physically or emotionally unsafe in your relationship with [partner's name]?

If the patient answers "yes" to any of these screening questions, then consider not performing partner notification services and instead explore other approaches.

11. Procedure

12. Methods

Annex D

13. HIV/STIs

14. Overview

(Insert infographic***)

15. Detailed

(Describe the PN process in detail, outlining the who, when, where, contact details, referral details, etc)

16. Viral Hepatitis

17. Overview

(Insert infographic***)

18. Detailed

(Describe the PN process in detail, outlining the who, when, where, contact details, referral details, etc)

19. TB

20. Overview

(Insert infographic***)

21. Detailed

(Describe the PN process in detail, outlining the who, when, where, contact details, referral details, etc)

22. Legal

23. National regulations

(Discuss the national and regional laws that govern PN in your country, making clear how staff are legally able to help patients through the PN process).

24. GDPR

The General Data Protection Regulation 2016/679 is a regulation in EU law on data protection and privacy for all individuals within the European Union and the European Economic Area. It also addresses the export of personal data outside the EU and EEA areas.

Article 9 of the GDPR specifically addresses health data (see below).

Article 9

Processing of special categories of personal data

1. Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited.

The GDPR prohibition on health data, does not apply under certain conditions, such as the following:

2. Paragraph 1 shall not apply if one of the following applies:

(a) the data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject;

• • • •

(h) processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, **the**

provision of health or social care or treatment or the management of health or social care systems and services on the basis of Union or Member State law or pursuant to contract with a health professional and subject to the conditions and safeguards referred to in paragraph 3;

(i) processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy.

(Describe country specific interactions with the GDPR here. For example, as Greek law requires voluntary patient referral, except in extreme cases, the GDPR should not affect the PN process).

It is important to remember that healthcare providers (HCPs)/ trained staff can still inform patients of multiple methods available for their use in PN, including:

Phone calls Contact slips Emails ICT tools Other resources

Patients are legally allowed to utilize any of these methods in patient referral, aka, without the involvement of HCPs.

NOTE: It is important to clarify the legalities of recording/managing partner contact details under the GDPR with your organization.

25. Interview

The Interview for partner notification should include the follow topics:

I. Introduction a. Introduce yourself b. State purpose/role c. Explain confidentiality
II. Patient Assessment
a. Patient Concerns
b. Social History
c. Medical History
d. Disease Comprehension
III. Disease Intervention
a. Partner Elicitation
b. Intimate Partner Violence Screening
c. Partner Notification Plan
d. Risk Reduction
IV. Conclusion and Summary

During the interview, healthcare professionals and designated staff will elicit information about the patients' sex, needle- sharing and close contacts as appropriate. They will assess for intimate partner violence (Annex C) and discuss and establish a partner notification plan with the patient. For additional guidance, more detailed talking points have been provided in Annex E for use by healthcare professionals and designated staff. This script is a guide and may be changed to fit specific needs/ contexts. Additionally, scripts* for use in phone calls, SMS, email and more can be found at AIDSfree.usaid.gov.

*Before using these scripts, first check with local laws and guidelines if healthcare providers are allowed to contact partners using any of these methods.

26. Tools

There are many tools available to help patients approach partner notification. These tools vary, allowing patients to notify partners through anonymous methods and ICT tools as well as more traditional methods.

27. Scripts

Whether the patient decides to notify partners in person, via SMS, phone call, letter or email, it can still be difficult to begin the conversation. There are many resources that offer example scripts for patients to use. Annex F includes some examples.

28. ICT tools

Some key populations may feel more comfortable utilizing ICT tools to notify partners. There are many to choose from, with many allowing the patient to remain completely anonymous. The EU joint action INTEGRATE has created a free online tool which can be found on the website ***. Other options, such as websites or apps, can be found in Annex F.

29. Monitoring

The ECDC recommends monitoring partner notification practices through clinical audits in order to develop interventions that improve outcomes (ECDC, 2015). INTEGRATE experts have suggested gathering data on the following indicators:

- % of patients with PN discussion done
- # of partners notified per index patient
- # and proportion of traceable partners per index patient
- # and proportion of partners contacted (mean, reported by index patient)
- # of partners attending clinic per index patient
- # and proportion of partners tested per index patient
- # and proportion of partners infected of the total # of contacts tested
- # of newly infected partners per index patient
- # and proportion of (infected) partners treated of the total numbers of partners infected
- # of partners treated per index patient
- Proportion of index patients with persistent or recurrent infections

30. Annexes

31. Annex A: Glossary

32. Annex B: Lookback Intervals

Look-back Intervals by Infection taken from 'BASSH Statement on Partner Notification for
Sexually Transmissible Infections' (2012)

Infection	Look-back Intervals for PN
Chancroid	All contacts since and in the 10 days prior to onset of symptoms.
Chlamydial Infection	Male index cases with urethral symptoms: all contacts since, and in the four weeks prior to, the onset of symptoms [†] All other index cases (i.e. all females, asymptomatic males and males with symptoms at other sites, including rectal, throat and eye): all contacts in
	the six months prior to presentation†
Epididymo- orchitis	Use the look-back intervals for chlamydial infection or gonorrhoea, if these are detected. If these infections are not detected, the look-back interval is for all contacts since, and in the six months prior to, the onset of symptoms [†]
Gonorrhoea	Male index cases with urethral symptoms: all contacts since, and in the two weeks prior to, the onset of symptoms [†] All other index cases (i.e. all females, asymptomatic males and males with symptoms at other sites, including rectal, throat and eye): all contacts in the three months prior to presentation [†]
Hepatitis A	Index cases with jaundice: all contacts in the two weeks prior to, and one week after, the onset of jaundice. Index cases without jaundice: if possible, estimate when infection is likely to have occurred based on a risk assessment. Notify the local CCDC, or equivalent, if an outbreak is suspected, there are household contacts, there are concerns about food or water borne infection, or the index case is a food handler.
Hepatitis B	PN should include any sexual contact (vaginal or anal sex, or oro-anal sex) or injection equipment sharing partners during the period in which the index case is thought to have been infectious. The infectious period is from two weeks before the onset of jaundice until the index case is surface antigen negative. In cases without jaundice, if possible, estimate when infection is likely to have occurred based on a risk assessment. In cases of chronic infection, trace contacts as far back as any episode of jaundice, or to the time when the infection is thought to have been acquired, although this may not be possible for long look-back intervals. Appropriate repeat serological testing of contacts should be offered. Arrange hepatitis B screening of children who have been born to infectious women, if the child was not vaccinated at birth, according to

	national guidelines. For screening of non-sexual contacts, including
	equivalent.
Hepatitis C	The infectious period for acute hepatitis C is from two weeks before the onset of jaundice. However, usually there is no jaundice or history to suggest acute infection, and the look-back period for PN is to the likely time of infection (e.g. blood transfusion or first sharing of injection equipment), although this may not be possible for long look-back intervals. However, PN should be offered in two situations only, where: There was vaginal or peno-anal sexual contact and either the index case and/or the sexual contact(s) have HIV infection Sharing of injection equipment occurred during the period in which the index case is thought to have been infectious Appropriate repeat serological testing of these contacts should be offered.
	Sexual transmission of HCV through heterosexual sexual contact is uncommon if both the index case and sexual contacts do not have HIV infection, and PN is not recommended for this group. Check that children born to women with hepatitis C infection have been tested for hepatitis C infection in accordance with nationally accepted guidance. For other non- sexual contacts thought to be at risk, discuss with the CCDC or equivalent.
HIV infection	An estimate, based on a risk assessment, of when infection is likely to have occurred should be made and PN provided to include all contacts since, and in the three months prior to, this estimate. If this is not possible, all previous partners should be contacted and offered HIV testing. The risk assessment should take into account sexual history, HIV testing history (including antenatal and Blood Transfusion Service testing history), and history of possible seroconversion illness. Additionally, any results for recent infection testing algorithm (RITA) assays10 for HIV infection, as well as CD4 cell counts and trend in CD4 cell counts should be taken into account, although careful interpretation of these data is needed.
	PN for HIV infection should be part of ongoing care. Joint Specialist Society Guidelines recommend sexual history taking at six monthly intervals after first presentation with HIV infection. Offer PN at follow-up visits when there are new sexual contacts whose HIV status is negative or unknown, or when new STIs are detected. Ongoing PN should include discussion about testing and re-testing of current partners and testing of children, where appropriate. Identifying undiagnosed HIV-positive children is a priority area of unmet need and practical guidance on the approach to HIV testing of children with HIV positive parents is available.
	Although there is no evidence-based guidance currently available, in a recent multi-disciplinary meeting the following were agreed: HIV PN should be initiated as soon as possible, and, by four weeks after a positive HIV test, agreed actions and timelines to resolve PN should be documented. Any outcomes of PN should also be documented at this time. Consensus that PN should be resolved by three months, but that if PN is still unresolved by this time it should be continued, with clear timelines,

	as successful PN outcomes have been reported up to 12 months after a positive HIV test.
LGV infection	All contacts since and in the four weeks prior to the onset of symptoms.
Non-specific	Male index cases with symptoms attributable to urethritis: all contacts
(nonchlamydial,	since, and in the four weeks prior to, the onset of symptoms†
nongonococcal)	
urethritis in men	(Screening of men, without clinical features suggesting urethritis, by
	microscopy is not recommended practice, and therefore PN is not
	recommended for this group).
Pelvic	Use the look-back intervals for chlamydial infection or gonorrhoea, if
disease	these are detected. If these infections are not detected, the look-back
uisease	symptomst.¶.
Phthirus pubis	All contacts since, and in the three months prior to, the onset of
infestation	symptoms.
Scabies infestation	All contacts (including non sexual contacts: those with prolonged skin-to-
	skin contact, bed and clothes sharing, and household contacts) since, and
	in the two months prior to, the onset of symptoms.
Syphilis	Early syphilis:
	o Primary syphilis: all contacts since, and in the three months prior to, the
	onset of symptoms
	vears prior to the onset of symptoms
	years prior to, the onset of symptoms
	Sexual contacts of index cases with early syphilis should have serological
	testing for syphilis at the first visit, and have this repeated six weeks and
	three months from the last sexual contact with the index case.
	Late latent and late syphilis: PN (of sexual partners and children of female
	patients) should be done back to the date of the last negative syphilis
	serology, if available. Otherwise, it should extend back over the patient's
	sexual lifetime as far as is feasible. Because of the possibility of congenital
	syphilis, consideration should also be given to the testing of mothers of
	where sub-optimal antenatal care was a possibility
Trichomoniasis	Any nartner(s) within the four weeks prior to presentation should be
111011011101114315	treated**

†If there have been no sexual contacts in these intervals: the most recent sexual contact beyond this interval.

||PN should be offered at follow-up visits when there are new sexual contacts, and to discuss re-testing of current partners and testing of children, where appropriate "The 6 month look-back interval for PID is given arbitrarily on the basis that Mycoplasma genitalium may cause disease in women and be asymptomatically carried in men and women for an unknown period. Also, false negative chlamydial nucleic acid amplification tests, as well as discordant chlamydial test results, and different rates of spontaneous clearance of chlamydial infection, between sexual partners, are possible.

**Trichomonal infection appears to resolve spontaneously in most men, usually within two weeks, with detection rates in men decreasing with increasing time from last sexual contact with female index cases. However, prolonged asymptomatic carriage has been demonstrated in some men.

33. Annex C: IPV Screening Tool

The following IPV screening tool was created using AIDSfree resources

With the patient, the healthcare worker/ designated staff member should review any partners where there is a risk or concern of violence. The screening for intimate partner violence includes four questions:

- 1. Has [partner's name] ever hit, kicked, slapper or otherwise physically hurt you?
- 2. Has [partner's name] ever threatened to hurt you?
- 3. Has [partner's name] ever forced you to do something sexually that made you uncomfortable?
- 4. Do/ did you generally feel physically or emotionally unsafe in your relationship with [partner's name]?

If the patient answers "yes" to any of these screening questions, then consider not performing partner notification services and instead explore other approaches.

34. Annex D: Flowcharts and Infographics

- 35. HIV/STIs
- 36. Viral Hepatitis
- 37. TB

38. Annex E: Healthcare Professional PN Talking Points

Talking points taken from AIDSfree resources

During pre-test information/counselling, providers should:

- Explain the importance of ensuring that all partners get tested for (HIV/STI/hepatitis).
 - (HIV/STI/hepatitis) infected partners can start on (HIV/STI/hepatitis) treatment to keep them healthy and reduce risk that they will pass (HIV/STI/hepatitis) to other sex partners and/or children.
 - Partners not infected with (HIV/STI/hepatitis) can access prevention services to help them remain uninfected, including condoms, pre-exposure prophylaxis (PrEP), and male circumcision.
- Inform the index client that:
 - The clinic is offering Partner Testing Services to assist the client to contact their partners so that these partners can learn their (HIV/STI/hepatitis) status.
 - The service is offered because we know disclosure of (HIV/STI/hepatitis) status to partners can be difficult.

- You will ask the client to list the names of all persons they have had sex with, including people they may have only had sex with one time. If there are also persons the client has shared needles with, you will also ask for their names.
- You will also ask for the names any child(ren) who may need an (HIV/STI/hepatitis) test.

During post-test counselling and/or counselling in the (HIV/STI/hepatitis) clinic:

- Remind the client of the importance of partner testing using information from above.
- Inform the client that there are 4 options for contacting their:
 - Client can contact the partner and let them know they should be tested for (HIV/STI/hepatitis);
 - The healthcare providers can contact the partners directly, without telling them the client's name (this will be done anonymously);
 - Client can contact the partner within a certain time period, after which the provider will offer assistance if the partner has not been tested;
 - The counsellor/provider can sit with the client and his/her partner and support the client as he or she tells the partner about their (HIV/STI/hepatitis) infection.
- If the client chooses option (3), they will have 4 weeks to bring in or refer their partner for HTS.
 - If the partner does not come in for HTS after 4 weeks, then the provider will contact the index client for permission to contact the partner.
- Inform the index client that:
 - \circ $\;$ All information will be kept confidential. This means that:
 - Partners will NOT be told the index client's name or test results.
 - The index client will NOT be told the (HIV/STI/hepatitis) test results of their partner(s) or whether or not their partner(s) actually tested for (HIV/STI/hepatitis).
 - You will NOT contact the partner without first contacting them to get their permission.
 - They will continue to receive the same level of care at this health facility regardless of whether they choose to participate in partner notification services.
- Answer any questions that the index client might have and obtain verbal consent to continue.
- Use the Index Client Form to record contact information for the index client.

39. Annex F: Patient PN Scripts

40. Talking Points for Patients

Make a Plan:

 Many people are afraid of telling their partner that they have (HIV/STI/hepatitis). It is helpful to make a plan

for how and when you will tell your partner.

- Think about how you would like to be told, if your partner was disclosing to you.
- Choose a day and a time when you and your partner will have time to talk.
- You also want to pick a time when your partner is not stressed or angry, and has not been

drinking alcohol.

 Pick a private place where you feel comfortable and safe. You may want to have someone in

the next room to help and support you, if needed.

Anticipate Reactions:

- Think about how your partner may react. Your partner may:
 - o Offer you support or comfort you
 - o Not believe it's true
 - o Feel confused or sad
 - o Feel angry
 - o Accuse you of bringing (HIV/STI/hepatitis) into the relationship or household
- Think about how you will respond to these reactions.
- What questions may your partner ask you? How will you answer these questions?

Start the Conversation:

- "I went to the clinic for a check-up the other day [or for xyz reason] and the doctor/nurse
 was encouraging people to get tested for (HIV/STI/hepatitis). So I got tested and learned
 that I have (HIV/STI/hepatitis). I wanted you to know so that you could also get an
 (HIV/STI/hepatitis) test. [If HIV] There are medicines now for treating HIV that can help
 us live a long time."
- "(HIV/STI/hepatitis) is very common in our community. I decided to go for an (HIV/STI/hepatitis) test. It turns out that I have (HIV/STI/hepatitis). I already started on treatment. I think it is important that you also get tested for (HIV/STI/hepatitis) so you can know your (HIV/STI/hepatitis) status."

Encourage Your Partner to Get Tested for (HIV/STI/hepatitis):

- Give your partner the Referral Slip
- Tell your partner that it is important they get tested for (HIV/STI/hepatitis). If they have (HIV/STI/hepatitis), they can get medicines to treat their (HIV/STI/hepatitis). These medicines can save their life and reduce the chance they will pass (HIV/STI/hepatitis) onto others.
- If they do not have (HIV/STI/hepatitis), there are things they can do to help them remain uninfected like use condoms, take pre-exposure prophylaxis, or get circumcised (if they are male).
- Offer support because this is difficult news for someone to hear. "We can work on this together. I will support you".

Practice First!

• Practice what you will say and do ahead of time. You can do that now with your health care provider or later by yourself in your home. This will help you feel comfortable on the day you actually tell your partner.

41. Example Letter for Patient Use

Here is an example letter for Chlamydia. More STI specific letter examples and fact sheets found at <u>www.letthemknow.org.au</u>.

Dear ___

Since I last saw you I've been told that I have Chlamydia. It's an infection that's passed on through sex. So, you might have this infection too. Even if you don't have any symptoms you can still have the infection.

The only way to be sure you are OK is to get tested and treated by your doctor. The treatment is easy and effective.

It's important to get checked because, if left untreated, Chlamydia can cause long-term health problems such as infertility.

I've included a fact sheet on Chlamydia and a letter you can take along to your doctor If you want to know more you can visit this website www.letthemknow.org.au/partners.html If you live in ______ call the Sexual Health Infoline on ______ to speak to a

sexual health nurse.

Sorry to give you this news but I'm concerned about your health and I thought it was better that you knew.

Regards

42. Anonymous Example Letter for Patient Use

Here is an example anonymous letter for Gonorrhoea. More STI specific letter examples and fact sheets found at <u>www.letthemknow.org.au</u>.

Dear _

This letter has been sent to you because someone you have had sex with has gonorrhoea. Gonorrhoea is a bacterial infection that can be passed from one person to another through sexual contact.

You may have gonorrhoea even though you don't have any symptoms. The only way to find out for certain is to be tested by a doctor.

Gonorrhoea is usually easily treated and we suggest you have the treatment even if your test shows you don't have the infection.

We have attached a fact sheet on gonorrhoea and a letter you can take to your doctor. Please don't ignore this letter because, if gonorrhoea is not treated it could cause painful medical complications for you. <u>www.letthemknow.org.au/partners.html</u>

If you live in ______ call the Sexual Health Infoline on ______ speak to a sexual health nurse.

Sorry to give you this news but I'm concerned about your health and I thought it was better that you knew.

Regards

Consortium





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