

# AN ANALYSIS OF CONTACT TRACING AND PARTNER NOTIFICATION PROCEDURES: POSSIBLE PROBLEMS, QUALITY REQUIREMENTS AND POSSIBLE SOLUTIONS TO THE PROBLEMS

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## INTRODUCTION

Prior to working out its proposals for European guidelines, the European Contact Tracing and Partner Notification (CT-PN) Group spent a good deal of time analysing the details of CT and PN procedures with the aim of highlighting all possible problems which could emerge for the physician, the psychologist and from the ethical and legal points of view. The aim of this work being to find possible solutions to these problems and list the quality requirements and framework within which to work in order to provide a “best practice” format for those in the field.

The work plan provided for the preliminary determination of a set of procedural rules, or a procedural algorithm, for ease of comprehension identifying the various stages and the kinds of choices which will have to be faced by the health worker during the actuation of CT and PN procedures.

The following aspects were systematically set forth and analysed on a step by step basis:

- Possible problems and risks inherent to the various forms of action to be taken.
- The limits and the quality requirements to be observed in seeking solutions ensuring due respect for the ethical, professional, legal and clinical principles contained in the proposals for guidelines.
- Possible operational solutions to each specific problem or ways of reducing the perceived risks

The method adopted was a step by step analysis providing those in the field with an explanation of the reasoning behind the guideline proposals and suggestions of how to overcome operational problems likely to arise when putting CT and PN procedures into effect.

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## PROCEDURAL ALGORITHM

As mentioned above an algorithm was worked out for the CT and PN procedure which mapped out the main decision-making points and the main strategies behind decision making.

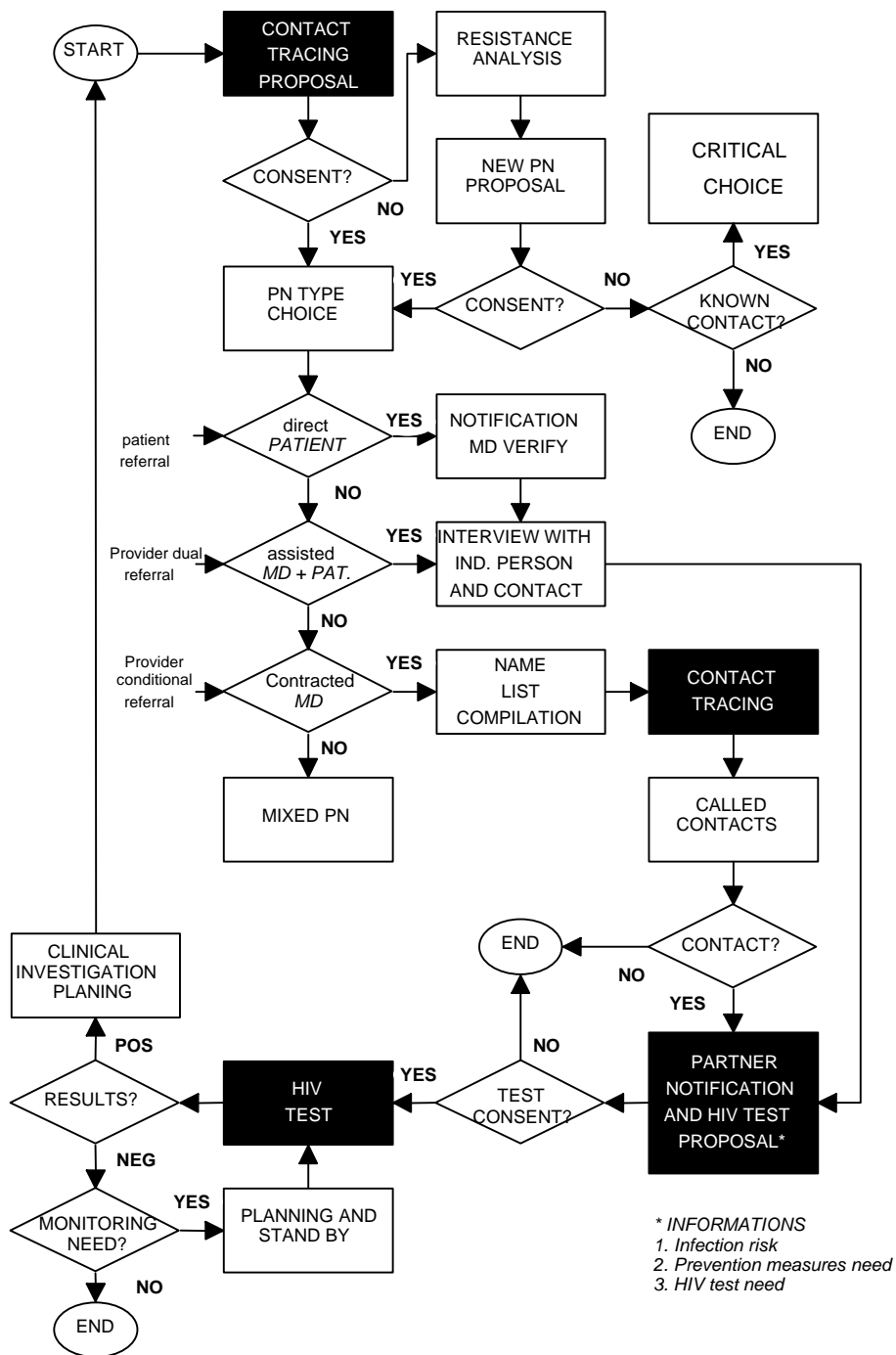
The starting point for the algorithm is the invitation to the index person to participate in or consent to the procedure.

When the index person expresses his agreement then the type of PN to be carried out has to be decided. If however he does not express his consent the health worker must analyse the reasons behind this resistance and then propose once again the putting into effect of CT-PN.

If, even after this second attempt, the patient continues not to consent to the warning of his partners and these partners are at actual risk and their identities are known to the health carer, a decision has to be made whether to observe the special confidential relationship with the patient or advise the partner(s) against the patient's wishes.

If the index person has given his consent to PN he may choose to advise his partners according to procedures most suited to the relationship with the partner, the trust between them and according to his own personal needs.

The choices which are available are *patient referral*, *provider referral*, *conditional referral* or some mix of these for different partners. If the patient or index person decides to have his partners contacted by the health carer, while remaining anonymous himself, the carer will start CT procedures to locate the partners who have to be told of the risk of infection, to inform them of the need to take preventive measures and to advise them to undergo HIV testing. Notification may also be by the index person directly or together with the health carer providing support. In any case testing must be proposed and, where there is consent, carried out.



## THE MAIN PROCEDURAL STEPS IN THE PROCEDURES

There is a general rule applying to the procedural model which needs to be stated before starting, i.e. the patient/client may at any time, even after having given his consent, decide to stop the procedures from going ahead and if this occurs the health carer must respect the patient's wishes.

The main steps in the CT and PN procedures can be summarised as follows:

<b>STEP 1</b>	Pre-test HIV counselling – Specific information for the client (possible index person) on CT and PN
<b>STEP 2</b>	HIV test
<b>STEP 3</b>	Post HIV test counselling for a patient found to be HIV positive – request for him to participate in the procedure
<b>STEP 4</b>	Evaluation and handling of the index person's response
<b>STEP 5</b>	Choice of the type of PN and collection and handling of the information provided by the index person
<b>STEP 6</b>	Partner/contact search, either by the patient or by the physician with the patient's express mandate
<b>STEP 7</b>	Contact with the index person's partners, with or without his presence but in any case respecting his wishes
<b>STEP 8</b>	Meeting with partner and notification of the risk to which the partner has been exposed, of the need for diagnosis and for the adoption of preventive measures
<b>STEP 9</b>	Proposal made to partner/contact to take an HIV test
<b>STEP 10</b>	Management of information return to the index person

## PRELIMINARY ANALYSES FOR THE CONSTRUCTION OF A MODEL

The table below shows preliminary analyses for the construction of a CT and PN model, the steps, problems, the quality requirements, the limitations and various criteria to be followed in working out possible solutions for the particular case.

<b>STEP 1</b>		
<sup>2</sup> <b>Pre HIV test Counselling – Specific Pre-Test information for the client</b> (possible index person) <b>on CT and PN procedures</b>		
<b>QUALITY REQUIREMENTS AND LIMITS</b>		
<ol style="list-style-type: none"> <li>1. The patient must be informed, during pre-test counselling, that if the test results are HIV positive then CT and PN procedures will be proposed.</li> <li>2. In advance of the test, the patient should be psychologically for the CT and PN procedures.</li> <li>3. The test must be permitted to be carried out even where acceptance by the patient is only conditional or where there is refusal to put the CT and PN procedures into effect should the test result be HIV positive.</li> <li>4. Pre-selection of patients to whom the CT and PN procedures should be proposed, i.e. those at reduced psychological risk. The procedures should not be proposed to those who could be potentially suicidal or unable to handle the situation.</li> </ol>		
<b>N.</b>	<b>1. POSSIBLE PROBLEMS AND RISKS</b>	<b>2. POSSIBLE SOLUTIONS</b>
1	Psychologically weak or potentially suicidal client who could become unbalanced on being informed of being HIV positive.	Assessment in pre-test counselling of the patient's psychological risk levels using standard macroindicators and medical records (e.g., considering any use of psychiatric drugs, periods of hospitalisation, previous suicide attempts or history of depression etc.).
2	Client psychologically not equipped to notify his partner of his state of infection.	The possibility of the patient himself putting into effect the CT and PN procedures must be made known to him at the pre-test counselling session. The physician must also offer his help and support whether the notification is carried out with the physician present or by the patient directly. This may ease the patient's worries about notifying his partner(s) even though this may not necessarily be the case as variations between individual cases have been clinically noted.

<sup>2</sup> Currently the preferred term for this is "pre test discussion" insofar as it is similar to counselling but the subject is treated more in the form of a conversation which is a discussion between people who are starting a working relationship aimed primarily at the exchange of information and knowledge and where the issues are largely to do with the problem of infection risks. Average discussion time is 10 to 20 minutes and often with staff who have little psychological training so it is not really accurate to refer to this stage as one of counselling "

<b>STEP 2</b>		
<b>HIV Test</b>		
<b>QUALITY REQUIREMENTS AND LIMITS</b>		
<ol style="list-style-type: none"> <li>1. The test should only be carried where out there is counselling and in a suitable setting</li> <li>2. The informed pre-test consent of the client should be obtained</li> <li>3. Laboratory test reliability is a requirement (labs that are duly accredited)</li> </ol>		
<b>N.</b>	<b>1. POSSIBLE RISKS AND PROBLEMS</b>	<b>2. POSSIBLE SOLUTIONS</b>
1	Unreliable laboratory methods where not subject to standard controls in accordance with European law.	Only accredited laboratories may carry out the HIV test. First a high sensitivity test with double sample control to be carried out.
2	Risk of false positives or test tube swaps	If positive, a new sample must be obtained and a high specificity recheck carried out before giving any reply to the patient.

<b>STEP 3</b>	
<b>Post HIV test counselling for patients resulting HIV positive Proposal to participate in the procedure</b>	
<b>QUALITY REQUIREMENTS AND LIMITS</b>	
<ol style="list-style-type: none"> <li>1. After an HIV positive result, the short term the priority must be to provide the patient with psychological support and establish a relationship of trust.</li> <li>2. The possibility must be given to the patient to revoke or make changes to his CT and PN consent at any time.</li> <li>3. The request to put the procedure into effect must respond to a specific need of the patient founded on proper and responsible reflection.</li> <li>4. The physician's offer to set the procedure into motion in accordance with the wish of the patient which may be suitably encouraged but not in any heavy-handed or coercive manner.</li> <li>5. Offering CT and PN must be considered by the physician as a prime duty and borne constantly in mind during the counselling and testing processes. It should not have an overly intrusive profile, be on a par with providing information on safe sex, and must in the end always be conditioned by the circumstances, condition and the wishes of the patient.</li> <li>6. CT and PN must go ahead only when there is the voluntary, unforced, and informed participation of the patient in the procedures.</li> </ol>	

N.	1. POSSIBLE PROBLEMS AND RISKS	2. POSSIBLE SOLUTIONS
1	The index person's being simultaneously told he is HIV positive and offered/requested activation of the CT and PN procedures.	If it meets the needs of the patient, the possibility should be considered of providing an emotional cooling off period before the procedures are offered, taking care however to immediately tell him of the need for preventive measures and to inform partners.
2	The patient's desire to change his mind and remove the consent he gave to CT-PN at the pre-test counselling stage, and to cut his ties with the health facility.	The patient must have the real possibility of withdrawing at any time from his relationship with the health carers and health facility without being pursued at a later date (thus respecting his right to anonymity). The continuity of the relationship must remain entirely the free choice of the patient.
3	The exertion of undue pressure on the patient by the physician in an effort to persuade him to accept the procedures	Specific informed consent for for CT and PN should be sought by listing the benefits and drawbacks inherent in the procedures. The patient should be reminded that it is "necessary, strongly recommended, usual and a moral duty" for him and for the physician to do their best to avoid the spread of the contagion to other people. It should be pointed out once again that the physician is willing, if required and if it is what the patient wants, to actively help or support the patient in the task of advising his partners.
4	The failure of some testing physicians to recognise the need to systematically propose the procedures to all HIV positive patients. CT and PN procedures being proposed in an occasional or non systematic fashion instead of to all patients who test HIV positive.	To build into the post-test counselling process an automatic CT and PN offering stage. To point out to the physician the direct consequences of his not doing the most he can to break the chain of the epidemic and of not following the guideline proposals, and thus of his personal responsibility for any further spread of the contagion.
5	A patient who is undecided or unconvinced of the need to activate CT and PN procedures.	The physician's proposal to the patient to participate in the procedures must take the form only of proposal for action which would be desirable. It should be free from any inquisitorial, control or stigmatising elements and any refusal must not prejudice the continuation of the doctor-patient relationship, also so that CT and PN can be proposed once again at a later date when the patient has had time to reflect on the situation.

STEP 4		
Assessment and management of the index person's response		
QUALITY REQUIREMENTS AND LIMITS		
<p>1. Breach of professional secrecy must, if it can be entertained at all, be considered exceptional and not generally or automatically applicable under any foreseeable circumstances. It must be considered only on a case by case basis after careful assessment of the situation. Such breach may be possible only under where the following conditions come together:</p> <ul style="list-style-type: none"> <li>• Repeated refusal of the HIV positive patient to advise his partner</li> <li>• Actual risk of the partner being infected</li> <li>• Direct knowledge of the index person's contacts by the physician</li> <li>• The presence of demonstrable just cause</li> <li>• The lack of any other possible ways of informing the contact of the exposure to risk</li> <li>• All possible attempts to convince the index person exhausted</li> <li>• The presence of express professional and legal rules which provide for the need to put the procedures into effect</li> <li>• Consent obtained from the professional association concerned</li> </ul> <p>2. The patient's agreement should be assessed in relation to his degree of awareness of the situation and his real willingness to proceed.</p> <p>3. The agreement of the patient to participate may be only partial, e.g. he may put down conditions and may revoke his consent at any time before the CT process is commenced.</p> <p>4. Obtaining "real" consent which is arrived at freely and formally expressed.</p>		
N.	1. POSSIBLE PROBLEMS AND RISKS	2. POSSIBLE SOLUTIONS
1	Total failure of patient to co-operate when the contact is known to the physician	The problem has not been solved, solutions are not unequivocally accepted and while some feel it should be left to the free choice of the physician others hold the view that the doctor-patient relationship should not be interfered with and professional confidentiality should be maintained. Action taken should observe limitation number 1
2	The patient accepts the procedures but this response may simply be a wish to placate the physician rather than being genuine acceptance.	Assessment at a later stage of the patient's positive response, leaving a brief time for any reconsidering of the original decision to comply.
3	The patient accepts the procedures with reservations, e.g. the patient wants some contacts to be advised without telling others.	The physician must accept the patient's conditions while using specific counselling aimed at overcoming this obstruction to the proper carrying out of the procedures.
4	Unreliable information and/or lack of spontaneous patient consent.	Obtaining real and informed consent in writing to participation in the procedures.



STEP 5
Choice of type of PN and collection and handling of the information provided by the index person
REQUIREMENTS AND LIMITS
<ol style="list-style-type: none"> <li>1. A single type of procedure should not be adopted nor should any one particular type be necessarily chosen over another in advance of an assessment of the case together with the index person, in an effort to see which is the most suitable procedure type for the type of partner, as conditioned by the type of relationship between the two individuals and the patient's own indications.</li> <li>2. The type of relationship which the patient has or has had with the contacts needs always to be analysed, e.g. whether conflictual, one of trust, or where there is any possibility of a violent reaction. Negative consequences for the index person in the form of unfortunate reactions from contacts advised must be avoided.</li> <li>3. In case of partner notification provider referral, the following characteristic must be ensured <ul style="list-style-type: none"> <li>• Preventive information should be given to the patient of the risks connected with the procedure and he should also be told that the drawing up of a list with his authorisation will be kept only temporarily and only for the purposes of CT and PN.</li> <li>• The list must be temporary and aimed only at the breaking of the epidemic chains.</li> <li>• The list must be immediately destroyed after the CT procedure has been carried out, itself being carried out as soon as possible, even if the CT has had a negative outcome.</li> <li>• The list must be kept in a different place from that in which the clinical records of the patient are kept, with no possibility of the two being linked i.e. the index person's records on the one hand and the names of contacts on the other.</li> </ul> </li> <li>4. The list may definitely not be used for any legal purposes, either in the present or the future.</li> <li>5. Any possible psychological risk, or suicide risk, of the contacts must be assessed by seeking information and indirect indicators from the index person where possible.</li> </ol>
<p>NOTE: In the carrying out of the CT and PN procedures it is frequently necessary for the health worker to draw up an epidemiological index person map in order to reconstruct, with his co-operation, all his contacts at risk of infection requiring preventive information.</p> <p>Being in possession of a formal list of contact names poses a range of important and still unresolved problems of both a legal and practical nature, in relation to its lawfulness, storage, use and protection. Any "linking" of these lists could lead bring to light a series of very personal relationships between individuals and involve a clear breach of their privacy if used for purposes other than lawful ones or ones exclusively of health service interest. It is not difficult to imagine how information of this kind, if badly handled, could pose a real danger of prejudicing the rights of the clients and patients even though they may, on the other hand, be indispensable instruments for the health workers' tasks.</p> <p>The matter must therefore be approached very seriously and rigorously.</p> <p>Some researchers maintain that, to ensure the preservation of rights, no list should be drawn up at all while others, though sharing the concern for proper storage and use, maintain that if the patient is properly informed of the possible risks related to keeping a list, its use, storage and the manner of its destruction before it is in fact made then it should be possible to formally draw one up. One partial solution may be, as with the index person, to preserve anonymity by assigning each name a code number. The CT and PN procedures are then carried out immediately.</p> <p>The problem does however remain, for example, of the passing on of a list to other health workers if the first working on the case ceases for any reason to handle that case. The transmission of lists formed in this way to numbers of people could give rise to not inconsiderable problems. Some authors have suggested that the list should be kept by the patient himself only. The proposals given here can only be considered as preliminary and do not therefore have the status of actual operational indications.</p>

N.	1. POSSIBLE PROBLEMS AND RISKS	2. POSSIBLE SOLUTIONS
1	<p>It is often not possible to use the same notification procedure for all partners as the relationships involved may be quite different. Some may be conflictual in nature and dangers may include provoking reactions against the patient, breakdowns in confidentiality, or of the emotional ties between the individuals.</p>	<p>It may be that the patient's refusal to participate in any way, or give his blessing to the procedures simply has to be accepted.</p> <p>If the patient's response is positive there are three types of procedure to be offered:</p> <ul style="list-style-type: none"> <li>• DIRECT – the patient himself tells the partner and the physician intervenes only later offering his help as a "consultant";</li> <li>• ASSISTED – the patient is directly assisted by the physician who is also present when the partner is informed;</li> <li>• DEFERRED – the patient provides the physician with the names of his contacts. The doctor then informs these and the index person's anonymity is preserved.</li> </ul> <p>The former case is known as "patient referral" and the latter as "provider referral".</p>
2	<p>The need to have information about the type of relationship between the index person and the contacts and the creation of a list of the patient's partners.</p>	<p>The creation of a "contacts map" also containing the nature of the relationship between the index person and resulting type of CT chosen by the index person.</p>
3	<p>How to safeguard and maintain confidentiality when there is a list of contacts. The keeping of the list could be unlawful or highly risky.</p>	<p>Strict separation of the index person's records and documents regarding contacts. Differentiated contact files also not linked even by code numbers to the index person.</p> <p>Highly controlled contemporary access to the list and the patient code, no longer even granted to the physician who received the index person's information.</p> <p>The health workers who obtain information on the index person must be different persons from those who then carry out the CT and PN procedures.</p>
4	<p>The risk of the court proceeding with the sequestration of the list. The list containing the names of the patient's contacts may have important legal consequences as official documentation in writing at the hand of the patient capable of constituting evidence in possible criminal trials, or indirect admissions of guilt by the patient.</p>	<p>The making of specific legislation providing that all documentation relating to the CT and PN procedures may not be used for legal purposes or requested by the court.</p>

5	Possible psychological risk to contacts or even risk of suicide when identified and notified during CT procedures.	Information can be gathered from the index person on the contacts by means of questions designed to elicit their general psychological make-ups, and particularly situations of evident risk. If possible and appropriate more detailed information can also be requested of the contacts' own physicians. Such action is however prohibited by the legislation in force in some countries.
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**NOTE:**

Even if a rare occurrence in practice, the patient could provide a list of false names or of known persons with whom he has not practised unsafe sex. This could occur as a result of some kind of grudge or the index person's desire for self-engrandisement.

What should be done if the index person gives the physician the names of false contacts or those with whom he has not been engaged in any behaviour at risk?

A psychological assessment of the patient should be carried out with a view to predicting whether there is any risk of this and the list must be checked through with the patient a number of times before starting the CT procedures. It does however remain an unresolved situation, albeit rare, with potentially serious consequences. The patient should be informed that if he were to supply any false information with a view to damaging any third party then the physician would no longer be bound by professional secrecy and the patient could lose his right to confidentiality as, in addition to committing a crime, the physician would effectively become an accomplice (a view not unanimously shared).

<b>STEP 6</b>		
<b>Partner/Contact search</b> (by either the patient or by the physician with the patient's express mandate)		
<b>QUALITY REQUIRMENTS AND LIMITS</b>		
1. The identification of the partner/contact must be certain before any information related to HIV risk and the reasons for the contact being made are given. 2. Only low error search methods should be used		
<b>N.</b>	<b>1. POSSIBLE PROBLEMS AND RISKS</b>	<b>2. POSSIBLE SOLUTIONS</b>
1	Incorrect identification of the partners/contacts indicated by the index person and the involvement therefore of extraneous persons.	<p>The health worker at the patient's home with a calling note containing only the following:</p> <ul style="list-style-type: none"> <li>• The name of the physician concerned;</li> <li>• The confidential case code number</li> <li>• No information about HIV problems</li> </ul> <p>The possible use of general practice physicians should be assessed. Some issues remain open in relation to costs, the intrusiveness of the action and diversity of legislation.</p>
<b>NOTE:</b> The common view of the health workers who carry out CT and PN tends towards the use of the telephone as the means of first contact. The client/contact should only however be told of the necessity of going to a health facility, not referred to as an AIDS/HIV centre or such like, in order to collect some personal health details which concern them (the nature of which the caller is unaware). The client/contact must be received by specialised staff who have the task of very clearly and directly explaining the reason and informative purpose of the meeting (regarding the risk run and needs arising from this).		

STEP 7		
<p align="center"><b>Contact with the index person's parnters</b> (with or without his presence but in any case respecting his wishes)</p>		
<p align="center"><b>QUALITY REQUIREMENTS AND LIMITS</b></p>		
<ol style="list-style-type: none"> <li>1. If the patient chooses deferred PN, all the procedures and tests must be carried out with complete anonymity assured giving the contacts no indications whatsoever about the index person or about any information received from him.</li> <li>2. The confidentiality of any information subsequently received from the contacts themselves must also be maintained, as against the index person, including the outcome of any HIV tests they may undergo.</li> </ol>		
N.	1. POSSIBLE PROBLEMS AND RISKS	2. POSSIBLE SOLUTIONS
1	<p>If the patient chooses to notify his partners/contacts by deferred PN, it is may sometimes happen that he will be identified by the contact insofar as the index person may have been the contact's only partner.</p>	<p>All deferred PN procedures must fully respect the anonymity of the index person and of the contacts by the use of numerical codes further reduing the likelihood of indentification.</p> <p>There does however remain the risk of indirect identification where a contact has only had one partner. This is a problem which cannot always be eliminated. The eventuality should be brought out before testing the patient as he must be aware of this possible problem before giving his consent to CT and PN.</p>

<b>STEP 8</b>		
<b>Meeting with the partner and notification of the risk to which the partner has been exposed, of the need for diagnosis and for the adoption of preventive measures</b>		
<b>QUALITY REQUIREMENTS AND LIMITS</b>		
1. A suitable confidential setting for counselling 2. When the contact enters the health facility his personal details must be destroyed and replaced by numerical codes, a fact of which the contact must be told while providing him with formal assurance that these data are not filed in any other places. 3. No information about the index person must ever be given to the contact nor any elements which could lead to his possible identification.		
<b>N.</b>	<b>1. POSSIBLE RISKS AND PROBLEMS</b>	<b>2. POSSIBLE SOLUTIONS</b>
1	The powerful psychological impact of notification resulting from the procedures brings the need for ways of containing the emotional response and properly handling the contacts	Health workers who are properly trained in counselling techniques, expert in CT and PN, observe the guidelines, are legally authorised and free from moralistic and judgmental attitudes.
2	Invasion of the contact's privacy. The existence of the "right not to know" of the risk to which they have been exposed and not to be tested.	The health worker should cease in his task when faced with a person who refuses to receive information or to be tested.
3	The contact objects to his personal details, as supplied by the index person, being in the hands of the health facility.	The destruction of the personal details in the presence of the contact/client. The use of a numerical code for the contact's clinical record. A written guarantee for the contact/client that the procedures to ensure his personal details are handled as anonymous data have been correctly carried out.
4	The danger of the index person and contact meeting on visiting the health facility.	This is a problem which is sometimes not easy to solve. The access point for the contact should be different from that of the index person, or at least scheduled for different times.
5	A request by the contact to learn the identity of the index person.	The health worker who notifies the contact must be different from the one who had previously interviewed the index person and is not in possession of any the index person's personal details.
6	The possibility that the contact is HIV positive and may therefore become in his turn, an index person.	Notification of the risk to which the person has been exposed and of the need to have an HIV test must be carried out in a context of counselling and anonymity. The person should be informed from the outset that if the outcome of the test is positive he will in his turn be able to avail himself of the CT and PN procedure.

STEP 9		
Proposal for and performance of the HIV test on the		
QUALITY REQUIREMENTS AND LIMITS		
1. HIV test to be carried out only if there is simultaneous provision of counselling and a suitable setting 2. To obtain informed consent before taking the sample 3. To ensure a short waiting time before receipt of the results of the test 4. The use of a test and suitable procedures to ensure a low probability of error		
N.	1. POSSIBLE RISKS AND PROBLEMS	2. POSSIBILI SOLUZIONI
1	High anxiety levels while patient is awaiting test results	Reductions in waiting times and provision of psychological support in the meantime
2	False positive result or test tube exchange error	A. The use of the Elisa + Western Blot test with double sample control ("probable" diagnosis) B. The taking of a second sample before giving a "certain" diagnosis and, in case of any remaining doubt, the carrying out of PCR

STEP 10		
Management of information return to the index person		
QUALITY REQUIREMENTS AND LIMITS		
Professional secrecy to be extended to the state of health of the contacts in the same way as it has been to the index person (two-way professional confidentiality)		
N.	1. POSSIBLE PROBLEMS AND RISKS	2. POSSIBLE SOLUTIONS
1	Possible inappropriate return of information about the state of health of the contacts to the index person (including indirectly)	The only return information which could be given to the index person regards the number of contacts it has actually been possible to reach as a result of his co-operation and information. The purpose of this would be put him in the best psychological position to be able to deal with any reactions there may be. This information about the restrictions placed on "information return" must be given to the index person before he compiles the list of contacts
2	Patient anxiety resulting from not knowing the effectiveness of the Contact Tracing and his consequently putting the health worker under pressure	To start providing specific psychological support while maintaining professional confidentiality and ensuring that there is no leakage even of the slightest information between counsellors and the CT and PN staff about the HIV status of the contacts examined

## **FINAL RECOMMENDATIONS**

This analysis of the procedures has taken a good deal of time and there has been a considerable amount of discussion due in large part to the unpredictable nature of the situations which arise as CT and PN are put into effect. There may be other situations not contemplated here which could be sources of further argument and detailed analysis of those who will be involved in this work in the future in the various countries. The requirements and limiting factors indicated here could be used in drawing up accreditation criteria (in correlation with specific indicators and standards) for the operational units which are called upon to carry out these activities within the countries' respective public health services. The proposed solutions should not be regarded as binding but as helpful indications which will necessarily have to be adapted and tailored to the social, cultural and legislative context in each individual country. To fully understand and best use this article it is necessary to simultaneously refer to the "CT and PN proposals for guidelines", the methodological and technical instrument for these activities.

## ENCLOSURE:

### Check list of the prerequisites for the activating of CT and PN in an individual case

When deciding if the CT and PN procedures may be activated a health worker's check list has been drawn up. The procedures should be put into effect when all the responses are affirmative. Even if one condition is not met and just one response is negative CT and PN may not be put into effect, at least until the problems determining that negative response have been solved.

N.	QUESTION	GO	STOP
1	Can the organisation assure adequate counselling, reliable results, suitable staff and confidentiality as required by the guide lines?	YES	NO
2	Is the patient HIV positive?	YES	NO
3	Was the index person informed of the existence of, benefits and drawbacks of CT and PN in pre – test counselling ?	YES	NO
4	Has there been freely formed and specific consent to CT and PN given or reaffirmed in post test counselling?	YES	NO
5	Have any conditions the patient placed on his consent been respected?	YES	NO
6	Has the patient been given the opportunity to revoke or alter his consent since the CT and PN procedures were first put into effect?	YES	NO
7	Has the real informed and willing consent of the patient been verified after allowing him some time for reflection on the decision?	YES	NO
8	Has the patient been provided with the opportunity of advising different partners in different ways according to the latter's' needs?	YES	NO
9	Has the patient been properly informed about how the health workers will actually carry out the CT and PN procedures?	YES	NO
10	Has the patient been informed of any legal risks connected with the compilation of a "contacts list", and has his consent to proceed been obtained?	YES	NO
11	Has the patient been informed that there may be a possibility of his being identified by a contact for whom he has chosen 'deferred' notification, and has his consent to proceed been obtained?	YES	NO
12	Has the psychological risk to contacts been evaluated?	YES	NO
13	Has the patient been informed that the only information which will come back to him with regard to the outcome of the CT and PN procedures is how many partners have been contact and the date of the contact?	YES	NO
14	Are there any contacts to be notified?	YES	NO
15	Have all the above criteria been observed?	YES	NO



We enclose the main points reached by the WHO in relation to CT–PN, account of which was taken in drafting the European document.

#### **Four points on the position of WHO and UNAIDS**

- Reporting, partner notification and disclosure of HIV/AIDS are procedures which are undertaken for a variety of purposes. They are procedures which are not always clearly defined and they take many different forms. The ways in which they are carried out depend on intended purpose, social context, characteristics of the individual or population group concerned, regulations in place, including those for the protection of human rights, organisation of health services, resources available, and prevalence of HIV. Recommendations on policy will be based on careful analysis of all these factors.
- As UN bodies, the role of WHO and UNAIDS is to advise States on public health policies that ensure respect for human rights. The AIDS epidemic has demonstrated that public health interest and respect for dignity and human rights are linked concerns. There is no antagonism between the two; sound policies and effective strategies must address them in synergy.
- WHO and UNAIDS recognise the importance of reporting and partner notification issues in relation to HIV/AIDS and understand the concerns of governments on this matter. We are gathering evidence on laws and policies and their impact from all parts of the world in order to provide a solid foundation for the formulation by governments of reporting and partner notification policies that fulfil their stated purpose, can be implemented safely and effectively and are in accordance with human rights standards.
- Governments need first and foremost to consider the intended purpose of proposed laws and policies. They must then examine the evidence that the intended purpose is, in fact, served by the proposed laws and policies; and assess the feasibility of their implementation and their likely positive and negative impact on individuals and societies.

#### **Partner notification and notification to family, friends or care providers**

1. Partner notification is an important way of protecting the uninfected partner, providing the information necessary to take protective action and an opportunity for education for prevention. It is also an important way of helping the already infected partner in terms of access to early treatment and care. Voluntary and confidential partner notification should be part of the standard of HIV/AIDS care, accompanied by psychosocial and medical care and support, including counselling, in a supportive environment which provides legal, material and social protection from negative consequences of disclosure.

2. The evidence that partner notification approaches are more effective when carried out on a voluntary rather than mandatory basis stems from combined experience in the history of sexually transmitted diseases and, more recently.
3. There is no strong evidence that mandatory approaches to notification are more effective than voluntary approaches
4. The issue of voluntary versus mandatory must be examined from a combined health and human rights perspective. Governments are responsible for the protection and promotion of public health, as well as for the protection and promotion of human rights. Thus, they have the obligation to devise public health strategies and policies that are respectful of human rights.
5. The burden of proof that the restriction of certain human rights in order to protect public health is necessary, rests with the government, and this evidence must be produced before, not after, the enactment of policy which restricts rights.
6. Public health experience shows that when people know that they will be asked to notify their partner(s), they are less willing to come for testing, treatment or counselling themselves. The net result then is that fewer people present at health centres, those that are infected continue to spread the infection to their partners, and care is not available to them or their partners.
7. It seems likely that the deterrent effect of forced notification on testing and treatment may result in greater spread of infection than that which would result from the absence of such a policy.
8. No, such legislation should not be enacted. WHO and UNAIDS strongly advocate, rather, for counselling of HIV-positive people on the importance of informing their partners and on their responsibility for the protection of their partner(s) health and their own.
9. On a voluntary basis, it is a very important way. It should be part of the standard of HIV/AIDS care. However, it is not a public health measure that can be applied in isolation. Any sort of partner notification must be accompanied by psychosocial and medical support and it must take place in a supportive environment which provides legal and material protection from the negative consequences of disclosure, including advocacy within the community for social support.
10. Partner notification should take place in a supportive environment which includes:
  - Voluntary counselling and testing with pre- and post-test counselling and respect for confidentiality
  - Care and support, including education for prevention, for the partner
  - Ongoing, long term medical and psychosocial support to ensure that people living with HIV/AIDS are cared for at all stages of infection and illness
  - Protection against physical harm such as violence, abuse, abandonment
  - Protection, including legal measures, against social and economic harm, such as loss of income, eviction from house/shelter, discrimination in employment or insurance cover.
11. The United Nations High Commission for Human Rights and UNAIDS have issued guidelines which clearly define the conditions which must be met for notification without explicit consent (OHCHR and UNAIDS, 1998). The guidelines state that:

“Public health legislation should authorise, but not require, that health care professionals decide, on the basis of each individual case and ethical considerations, whether to inform their patients’ sexual partners of the HIV status of their patient. Such a decision should only be made in accordance with the following criteria:

- The HIV positive person in question has been thoroughly counselled
- Counselling of the HIV positive person has failed to achieve appropriate behavioural changes
- The HIV positive person has refused to notify or consent to the notification of his/her partner(s)
- A real risk of HV transmission to the partner(s) exists
- The HIV positive person is given reasonable advance notice
- The identity of the HIV-positive person is concealed from the partner(s) if this is possible in practice
- Follow up is provided to ensure support to those involved as necessary.”

## II SPECIAL SECTION CONTRIBUTION

# **AN ITALIAN EXPERIENCE IN CONTACT TRACING AND PARTNER NOTIFICATION. THE MODEL USED BY THE HIV SCREENING SECTION**

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## **INTRODUCTION**

The purpose of the research is to present a model of contact tracing and partner notification (CT-PN) designed by the HIV Screening Unit of a local health department in Verona.

Here is a brief description of the basic aims of the study, the results achieved and the difficulties encountered. A cost-benefit analysis, which we consider one of the most interesting aspect of CTR-PN, is also reported.

## **AIMS OF THE STUDY**

The basic aim of the study was to develop an Italian model of contact tracing and partner notification targeting HIV seropositive patients (index patients) and aimed at interrupting the epidemic of HIV infection, offering all individuals found to be infected suitable counselling and medical care.

The collected data are from a preliminary survey carried out in order to design a suitable programme.

Secondary objectives of the research were:

- 1) to test the acceptance of the programme by the patient;
- 2) to assess the number of index patients unwilling to inform their partners (occasional or not);
- 3) to point out the difficulties that index patients can come across in notifying sexual and/or needle-sharing partners of possible risk;
- 4) to estimate the number of index patients who implemented partner notification and to assess how they dealt with it;
- 5) to estimate the number of patients who have accepted the proposed programme;
- 6) to report the number of partners notified;
- 7) to assess how the notification was carried out;
- 8) to evaluate how many partners contacted were tested resulting HIV positive.

## **DEFINITION OF “CONTACT TRACING “AND “PARTNER NOTIFICATION”**

By the term contact tracing we intend all the procedures adopted by the public health counsellor, in agreement with HIV positive individuals, aimed at tracing all partners with whom they have been engaged in behaviour at risk.

Contact tracing is a delicate practice as moving in the social environment of the individual to be traced, asking questions of strangers, requires very careful and tactful treatment.

An effective means of carrying out a preliminary survey is by telephone.

Partner notification is the notification of all sexual or needle-sharing partners of seropositive persons of the potential risk and of the necessity of having an HIV test.

Partner notification can be conducted in different ways.

The index patient is the person found to be HIV positive who has not informed his partners of the potential risk.

The contact is the individual who has had unprotected (without condom) sexual intercourse with the seropositive patient, or has shared a needle with him.

## **METHODS**

Contact tracing and partner notification is a particular method of recruiting the contacts of the HIV positive persons and of notifying them, through health professionals, of their potential risk of infection.

It is carried out with the voluntary cooperation of the HIV positive patient who is encouraged to provide the health counsellor with the names of his partners. The counsellor will then manage to contact them supplying all the necessary information, but without revealing the identity of the index patient with whom they have had sexual intercourse or shared needles.

### **Direct notification, assisted notification, delayed notification, geographical disorientation.**

The HIV-positive individual can inform his own partners of their potential risk of infection using different methods and strategies: through "delayed communication" or through "assisted communication".

It is up to the patient to decide which is the most suitable means from among the following:

1. Direct notification: the HIV-positive individual personally informs his current and past partners of his infectious status. This usually happens in a non-medical setting and it is not possible to check the quality of the information provided, nor to assess the effectiveness of the intervention, nor to be sure that the notification was really carried out. With regard to this last aspect, in order to be sure of the notification of the partner has impact taken place, it is necessary to ask to examine the partner. This method is usually adopted for notifying those partners with whom the patient has a stable relationship. Nonetheless, within the proposed model, it is considered the least effective if the health care provider does not contact the partner afterwards.
2. Assisted notification: notification is carried out with the counselling of a health care provider who has previously agreed with the patient on the strategies to be adopted. In this case the setting is provided by a health department. The method means less apprehension for the index patient and the transmission of more correct

information to the individual contacted who is, in most cases, already partially aware of his potential risk.

It is usually chosen by the index patient to inform those partners with whom he has a stable relationship; yet, it proves to be more difficult when the relationship is occasional. In this case, in fact, even if the HIV positive patient can trace the occasional partners, it can be difficult to persuade him to come to the health care establishment so as to notify him his own infectious status, also because the occasional partner could live in another town or region.

3. Delayed notification: the index patient, maintaining anonymity, supplies names and elements necessary to trace his partners, leaving to the counsellor the task of tracing and notifying them of their potential risk of HIV infection. Partners can, in such a way, be informed of the risk and the index patient can avoid further apprehension in addition to being HIV positive.

Delayed notification is a much more practicable method especially with the occasional partners. Yet, without the help of a counsellor to the index patient in this delicate task, occasional partners would come to know of their potential risk of infection. The practice is helpful also because it allows the index patient to maintain his anonymity and, at the same time, it gives the partner the right to be aware of their potential risk. Furthermore, it helps the HIV-positive patient to reduce his anxiety caused by the sense of guilt for infecting, even accidentally, other people.

*“Geographical disorientation”* : in case of patients with a single partner living in small urban areas, even with a delayed notification, it would be easy to identify the index patient. In order to avoid the identification of the index patient, health professionals of other towns can be asked to implement contact tracing and partner notification procedures, so as to create a sort of “geographical disorientation”.

In delayed notification the first setting is usually provided by the telephone and afterwards by a health department. This is a very effective and quick way of tracing people even if it presents many difficulties (that can, anyway be overcome) due to the strong emotional impact on both the subject contacted and the health professional.

According to some authors it is the most effective and appropriate procedure. It is, in any case, necessary to stress the importance of keeping the identity of the index patient secret from the individuals contacted. Much attention must be paid to not providing any element even indirect, that could somehow lead to the identification of the HIV-positive subject.

For this reason only a health professional who does not know the index patient should carry out partner notification, so as to avoid accidental disclosure of information that could reveal the identity of the index patient. Furthermore, the health provider will not, for any reason, disclose to the index patient either the test results of the partners contacted or information on the number found to be HIV-positive. Among the partners referred by the index patient it is likely the person responsible for the infection transmission to be identified. The individual could be totally unaware of his HIV-positive status or he could be aware but unwilling to adopt preventive measures. Should the index patient suspect this last possibility, serious conflicts would emerge, though it is almost impossible, on the basis of what the patient and the partner refer, to obtain the correct epidemiological sequence.

## METHODS OF CONTACT TRACING AND PARTNER NOTIFICATION

Proposal to the HIV positive patient of the contact tracing and partner notification programme:

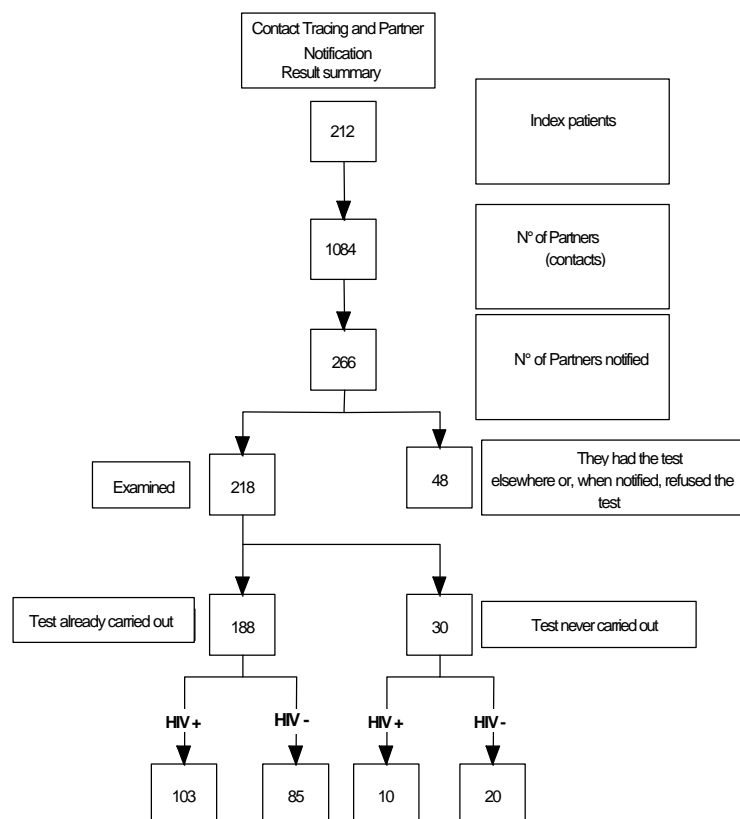
1. The health professional explains and proposes to the HIV-positive subject (index patient) the contact tracing and partner notification programme.
2. He tries to find out if the index patient has already notified his occasional and stable partners, past and present (contacts) with whom he has not adopted preventive measures of their potential risk of infection.
3. If the patient refers risky behaviour with partners not aware of their potential risk, the health carer deals, together with the patient, with the notification to them, assessing carefully all the difficulties that can be encountered and all the possible methods of notification to be adopted for each single partner;
4. He invites the HIV-positive patient to personally inform his partners of his HIV-positive status (direct notification) and offers him his help in doing so with the greatest of confidentiality (assisted notification).
5. If the patient is not able to cope with the situation on his own he gives his help in contacting the partners directly and in informing them of their potential risk (delayed notification). The patient provides all the information necessary to trace his partners (telephone number, address etc.).

The delayed notification can be carried out through different methods:

	<b>Advantages</b>	<b>Drawbacks</b>
<b>By telephone</b>	<ul style="list-style-type: none"><li>• It is easy and not expensive</li></ul>	<ul style="list-style-type: none"><li>• The identification is not certain</li></ul>
<b>By letter</b>	<ul style="list-style-type: none"><li>• It is easy for the health professional to carry out</li></ul>	<ul style="list-style-type: none"><li>• The letter can be opened by other people</li><li>• There isn't the possibility to be face to face with the partner</li></ul>
<b>Through the health provider</b>	<ul style="list-style-type: none"><li>• Possibility to be face to face with the partner</li><li>• Certain identification of the contact</li></ul>	<ul style="list-style-type: none"><li>• It is expensive,-exacting, intrusive,</li><li>• Not practicable with patients living out of town (only with patients within 10 km)</li></ul>



## RESULTS



Contact tracing and partner notification procedures were proposed to 212 HIV-positive patients. The most represented group was composed of males (67 %) ex-intravenous drug users (35%). The second group of the experimental sample was made by heterosexuals (25%), most of whom had had past sexual intercourse with drug users (49%). The average age was 35.2 (DS=7.5).

Here is a summary of the results:

1. approximately 29% of index patients supported entirely the programme; 48% only partially, 23% refused it;
2. 41% of index patients only had stable partners, whereas 8% just occasional partners; 50% had both stable and occasional partners; 1% did not have either stable or occasional partners. The total number of stable partners contacted was 300, while the occasional partners referred were 784 (approximately 1310 occasional partners were referred by 7 index patients who were prostituting themselves and by 5 homosexual patients with highly promiscuous sexual behaviour).
3. 214 stable and 52 occasional partners were informed of their potential risk of infection;
4. direct notification proved to be the main method used by index patients to notify of their potential risk of infection to stable partners (93.9%) and occasional partners (78.8%); 21.1% of occasional partners were informed through delayed notification;

The table below gives a summary of the results achieved:

	Contacts referred		Total number (%)
	Stable N (%)	Occasional partners (%)	
<b>n° of partners referred</b>	300 (27,6)	784 (72,4)	1084 (100)
<b>n° of partners notified</b>	84** (13,3)	732 (86,7)	814 (100)
<b>n° of partners not notified</b>	214 (80,4)	52 (19,6)	266 (100)
<b>n° of partners notified through direct communication</b>	201 (93,9)	41 (78,8)	242 (91)
<b>n° of partners notified through assisted communication</b>	9 (4,2)	0	9 (3,4)
<b>n° of partners notified through delayed communication</b>	4 (1,9)	11 (21,1)	15 (5,6)

\*\* 84 stable partners were not contacted either because they were dead or because considered by the patient the source of the infection and therefore excluded.

- 102 (51.3%) stable and 11 (57.9%) occasional partners had the HIV test done resulting HIV-positive, 6 partners (2 stable and 4 occasional) were informed of their potential risk through delayed notification, using the “geographical disorientation.

Contacts	Partners notified (%)	Partners not notified (%)	Partners tested (%)	HIV-positive (%)	HIV-negative (%)
<b>Stable</b>	214 (100)	15 (7)	199 (93)	102 (51,3)	97 (48,7)
<b>Occasional</b>	52 (100)	33(63,5)	19 (36,5)	11 (57,9)	8 (42,1)
<b>Total n°</b>	266 (100)	48 (18)	218 (82)	113 (51,7)	105 (48,5)

- 30 individuals unaware of whether they more positive HIV had the HIV test after counselling ; 10 resulted HIV-positive, 20 HIV-negative. 18 were notified of their potential risk but it was not possible to know the HIV status either because they were tested in other health departments (ref. delayed notification and geographical disorientation) or because they refused the test after the counselling of the health provider;
- the reasons leading to partner notification are mainly: the respect of their partners (67.2%), the fear of infecting them (25.9%), the loyalty and honesty towards them (19%), the emotional involvement with their partner (12.1%);
- the reasons leading to non- notification of partner are: fear of being abandoned (53.8%), the possible spread of information by the partners and other people (40.6%), the fear of being discovered and judged (38.5%).

9. Most of the patients notified their stable partners of their own HIV status immediately (68.5%), a small percentage after a few days (7.1%), whereas others a few weeks later (11.5).
10. Of the 21 individuals, being asked which was the most appropriate moment to carry out contact tracing and partner notification procedures, 69.2% replied that they should be proposed at the same time as the notification of the HIV positive status.
11. the costs/benefits estimate, reported below, emphasized the economic advantage of this programme:

N. of index patients	Costs of CT and PT procedures	New infections avoided	Money saved
100	85.500.000	3	1.500.000.000

12. Even considering the economical aspect alone, and disregarding ethical matters and, the individual and social suffering that each new infection involves, the above figures are clearly in favour of this programme;
13. One of the most important aspects emerging from the results is the high percentage of HIV positive women (F=21, M=6) infected by index patients defined as heterosexual individuals with risky behaviour.  
The figure, like the others reported above, refers to HIV positive individuals among the number of partners tested. Then there are the women infected by ex drug users (F=22, M=20), followed by the partners of homosexual index patients (M=26).  
The group made up of ex and active drug users was the most frequent within the sample considered. This involves a series of difficulties about contact tracing and partner notification procedures. Index patients, find it often difficult to get information on their partners especially if they are needle-sharing partners or prostitutes.

## COMMENTS

It is evident, also from the results of the research, that, as HIV is a sexually transmitted virus, the relations and sexual behaviour of the patients with their partners should be at the heart of the intervention aimed at preventing new infections. Sexuality is not always an easy subject to deal with by health personnel. Medical training in fact, does not include the development of skills in individual and couples psychological counselling as far as sexual transmitted diseases. Contact tracing and partner notification procedures require special knowledge and skills of the trained health department staff as they have to be able to:

1. deal with delicate topics like sexuality, individual and couples counselling ;
2. communicate with patients;
3. establish relationships of mutual trust without being judgmental;
4. understand the difficulties of the patient and give him all the necessary time to solve the problems;

5. create, at least at the very beginning of the relationship, a sort of alliance with the patient, accepting his excuses for not carrying out partner notification;
6. propose contact tracing and partner notification procedures to him only at a later moment, if necessary;

From the research, carried out with the cooperation of some medical personnel, the health professional has proved to be in difficulty in dealing with the potential risk of the patient of infecting other people. Sometimes it seems that he wants to protect the patient already extremely tried by misfortune, by intervention that could violate his privacy.

For the medical staff it can be difficult to deal with patients with sexual problems.

Medical urgencies involved in the infection are perceived as priorities over other kinds of intervention. It is as if the doctor, even aware that the patient could infect other people, does not want to share the responsibility and ethical weight.

There is the patient who is visible in the flesh and there are hypothetical patients without a face and without a history that the doctor seems unconsciously not to support (partners at risk). It is as if the doctor did not consider that the HIV-positive patient could have an active sexual life. The questions the health professional asks the patient relate just to the use of condoms. In case the doctor, for example, has both members of a couple in his care, he takes their mutual faithfulness for granted (which proves often to be hypothetical once he examines individually the external relationships of each single partner). After the initial anamnesis, they are requested if they have other partners external to their relationship, as can happen for HIV-negative couples submitted to HIV test monitoring. It seems that patients cannot have any form of sexual activity.

The special training of health professionals on this particular aspect would therefore allow to better deal with contact tracing and partner notification.

## CONCLUSIONS

The interest shown by patients in CT and PN procedures is evidence that it is necessary to deal with the notification of partners of their potential risk in a strictly confidential context. Yet, considering all the possible epidemic chains that can be generated at any moment by the index patient, it is not possible to exhaust CT and PN program just with one intervention.

The programme should be submitted to the patient times. A study in fact, refers an increase of 16% of cases notified, if the procedures are offered to the index patient more than once. Furthermore, some authors several emphasized that infection capacity does not only vary from individual to individual but in the same individual in different moments of life. Partner notification should be considered a standardized procedure among the services offered to the HIV+ patient.

The difficulties encountered by the patient in dealing with the procedures are reported in the results which emerged from the questionnaire on the reasons causing patients not to inform partners of the potential risk. A detailed sexual and drug use anamnesis in a pre-test counselling context is a basic instrument for carrying out correct CT and PN procedures, in order to come to an agreement with the patient on the best way of

notifying each single partner of his potential risk. It is important, in any case, to point out that even if the results obtained up to now are undoubtedly encouraging, from this study it is possible to get only some information on CT and PN procedures, as the data are still partial and need further investigation.

The research was carried out by a local health unit that did the test in anonymity, unlike what happens in other hospital health departments for infectious diseases that most of HIV-positive individuals apply to.

Sample recruiting, even if randomized within the same unit, cannot be considered representative of the general population of HIV-positive individuals. On the other hand, the offer of the test in anonymity and the avoidance of stay hospital departments can have effectively selected the sample interviewed.

The data collected can undoubtedly contribute to the use of Contact tracing and partner notification procedures, today still controversial in our country. The study has been funded by the AIDS Research Project of the Ministry of Health (I.S.S.).

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# **PARTNER NOTIFICATION FOR HIV INFECTION. AN OVERVIEW AND THE EXPERIENCE IN ENGLAND**

*Kevin Fenton*

## **SUMMARY**

Partner notification is that public health activity in which the partners of individuals with an infectious disease are notified, counselled about their exposure and offered services.<sup>1</sup> The primary objective is to notify partners at risk so that uninfected partners might avoid acquiring infection and infected partners might avoid transmitting infection. Ultimately, partner notification aims to reduce the burden of disease in the community.<sup>1</sup>

Partner notification has been shown to be an extremely effective way of controlling the spread of some sexually transmitted diseases (STD), e.g. gonorrhoea and chlamydia infection.<sup>2</sup> It has been recommended as an intervention strategy to prevent HIV transmission<sup>3,4</sup> alongside HIV counselling, testing, sexual health promotion and the social marketing of condoms.<sup>5,6,7</sup> This has been controversial, as there has been little evidence to support its effectiveness, safety, acceptability and appropriateness. Nevertheless, national policies and guidance promoting HIV partner notification have now been developed in many countries including the UK.<sup>8,9</sup>

However, despite national guidance and more than a decade after the onset of the HIV epidemic, HIV partner notification is not being delivered in many GUM clinics.<sup>10</sup> The reasons for this are unclear. Unsupportive attitudes among health care workers<sup>11,12</sup> and unclear professional responsibilities,<sup>13,14</sup> especially in London, may have an impact, but this has never been formally evaluated.

## **THE UK HIV EPIDEMIC**

By the end of June 1997, 29, 599 cases of HIV and 14, 431 cases of AIDS had been reported in the United Kingdom since reporting began in 1982.<sup>15</sup> Most (61%, 17,954) of those infected were thought to have acquired their infection through sex between men, 20%(5,804) through heterosexual intercourse, and the remainder through parenteral or vertical transmission. Among those infected heterosexually, the majority (75%, 4329) was presumed to have acquired their infection outside the UK (having lived or visited abroad), with approximately 85% being exposed in Africa.

The increasing utilisation of combination antiretroviral therapy has resulted in a reduction in AIDS reports over the past 18 months.<sup>15</sup> Nevertheless, sustained primary HIV prevention interventions are necessary to prevent the growing problems of relapse to unsafe sex behaviours among at risk groups,<sup>16</sup> and STD transmission.<sup>17,18</sup>



## PARTNER NOTIFICATION: RATIONALE

Partner notification has been a core activity in STD control in the UK for more than 40 years.<sup>19</sup> It has been shown to be effective in controlling treatable STD e.g. gonorrhoea and chlamydia in the community.<sup>2</sup> Table 1 summarises some of the proposed benefits and costs of partner notification to individuals, their contacts and the community. They have been poorly quantified.

For individuals, partner notification allows the opportunity for focused counselling and support, discussion about safer sex and behaviour modification. It may however be seen as intrusive and associated with confidentiality concerns if there is a risk of being identified by partner(s).

**Table 1.** Potential benefits and costs of partner notification.<sup>20</sup>

	Benefits	Costs
Patient	<ul style="list-style-type: none"><li>• Counselling</li><li>• Support to inform partners</li></ul>	<ul style="list-style-type: none"><li>• Threatening or intrusive</li><li>• Confidentiality concerns</li></ul>
Partners/ Contacts	<ul style="list-style-type: none"><li>• May reduce the likelihood of acquiring or transmitting infection</li><li>• Improved prognosis because of earlier diagnosis</li><li>• Counselling and support</li><li>• May result in behavioural change.</li></ul>	<ul style="list-style-type: none"><li>• Threatening or intrusive</li><li>• Confidentiality concerns</li><li>• Domestic violence</li><li>• Social ostracisation</li></ul>
Community	<ul style="list-style-type: none"><li>• Reducing the burden of disease</li><li>• Improved surveillance, identification of disease networks, dissemination of information</li></ul>	<ul style="list-style-type: none"><li>• Opportunity costs: Could partner notification funds be better used elsewhere?</li><li>• Intrusion of state on individual rights</li></ul>

For partners, notification may cause anxiety and be seen as threatening or intrusive. Domestic violence,<sup>21</sup> loss of confidentiality and social ostracisation, as a result of partner notification have been reported. These complications underscore the need for careful consideration and support to be given to those involved in the process.

## THE LEGISLATIVE FRAMEWORK IN ENGLAND

To date, in England and Wales, there are no legal requirements for persons diagnosed with HIV infection to inform their partners. Guidelines on partner notification have however been issued by professional bodies and the Department of Health. In general, the professional guidance have focused on clarifying the role and responsibilities of the professional in the relationship with the index patient and their contacts. The governmental guidance has focused on when, where and how to implement PN programmes. None have presented any single preferred model for PN or examined legal risks to patients or their contacts.

As early as 1988, the BMA recommended that doctors did have the right, as a last resort, to tell a wife or lover that a partner was HIV positive thus freeing doctors to protect the interest of those perceived to be at risk. In July 1992, the Society of Health Advisers in Sexually Transmitted Diseases (SHASTD) issued a statement which noted that the responsibility of informing partners basically lies with the individual with HIV infection and that any notification, whether it is done by the patient or the health adviser, must have the patient's full agreement and consent. This apparent conflict with the BMA's recommendation highlighted some of the professional divisions in attitudes.

The Department of Health (DoH) issued guidance on the implementation of HIV partner notification programmes in GUM clinics in December 1992.<sup>9</sup> It aimed to encourage the development of local clinic policies and, at minimum, the routine discussion of partners with each newly diagnosed HIV positive patient. It was distributed to managerial level staff within the NHS including Regional Directors of Public Health, Consultants in Communicable Disease Control, Chief Executives of NHS Trusts and District Directors of Public Health. GUM consultants and senior health advisers were not included in the distribution however the guidance recognised that managers would need to consult with local GUM medical, nursing and health advisor staff in the development of policies.

The guidance discussed in detail the rationale, benefits and disadvantages of HIV partner notification, confidentiality and methods of implementation in GUM clinics. It was not prescriptive and did not promote HIV partner notification as a compulsory activity. It recommended a number of practice standards some of which are summarised in Table 2 below.

**Table 2.** Standards for the delivery of HIV partner notification as outlined in the DoH guidance.

Key area for implementation	Recommendations as outlined in the guidance (paragraph number)
Development of local policies	<ul style="list-style-type: none"> <li>• All GUM clinics should have developed local clinic policies and guidelines on HIV partner notification.</li> <li>• Policies will vary according to local prevalence, populations served and geographic setting. (18)</li> <li>• Policy development should involve skills of multiple professionals within the GUM service. (19)</li> </ul>
Timing of HIV partner notification	<ul style="list-style-type: none"> <li>• Preliminary discussion should be part of every pre-test discussion about HIV testing. (22)</li> </ul>
Responsibility for HIV partner notification	<ul style="list-style-type: none"> <li>• Ultimately each HIV infected individual will make his or her own decision whether and how to inform partners. (23)</li> <li>• Health workers responsible for informing a person must be prepared to discuss how partners are to be told. (23)</li> </ul>
Discussing HIV partner notification	<ul style="list-style-type: none"> <li>• A variety of workers may be called to give an HIV positive result. Appropriate training for these workers is essential to enable them to discuss partner notification. (24)</li> <li>• The special skills of a health adviser may be needed to undertake provider referral. (25).</li> </ul>
Training	<ul style="list-style-type: none"> <li>• Employing authorities have the responsibility to ensure that the skills associated with partner notification are enhanced for all care professionals involved in the process. They need to provide specific education and training for all health advisers. (26)</li> </ul>
Ubicazione	<ul style="list-style-type: none"> <li>• Managers should ensure that those found HIV positive in other settings [outside GUM] are offered support and counselling about partner notification. (27)</li> </ul>

## **STRUCTURE: HIV PARTNER NOTIFICATION IN ENGLAND**

In England and Wales, the diagnosis and management of STDs including HIV infection is undertaken by a network of over 200 Genitourinary Medicine (GUM) clinics. Wide variations exist in clinic characteristics with those in London seeing more patients and diagnosing more cases of STD and HIV infection than elsewhere in the country.

STD partner notification is the responsibility of Health Advisers (formerly contact tracers) many of whom had entered the profession via public health/ community nursing. Increasingly however health advisers are drawn from a more diverse population including health promotion, clinical nursing, education, counselling etc. Apart from contact tracing, health advisers provide a range of services including counselling, sexual health promotion, health education and behavioural research.

At present, there is no national training programme for health advisers and many receive “on the job” training and experience in partner notification. The Society for Health Advisers in STD (SHASTD) - a national professional organisation - has made some attempt to set practice standards and develop practice guidelines. However the lack of national guidance on appropriate HIV partner notification practice has meant that many clinics are not adequately prepared

## **PROCESS HIV PARTNER NOTIFICATION IN ENGLAND**

There are three main components to HIV partner notification programmes in Britain:

- Post-test counselling
- Notifying partners at risk
- Offering counselling and HIV testing to located partners<sup>1,22</sup>

### **HIV post-test counselling**

HIV test results are usually given by physicians, however in some clinics, especially in inner London, results may be given by nurses or health advisers. In event of an HIV positive result patients are often referred immediately to a health adviser for counselling and support. Discussion about partner and partner notification may occur at this initial visit, but it is quite often deferred to allow patients time to adjust. It is then the health adviser's responsibility to determine a more appropriate time revisit partner notification discussion.

This involves four steps: Obtaining a detailed sexual history, discussing partners, agreeing the notification period (time period between presumed infection and diagnosis) and identifying partners at risk within this notification period (through sexual intercourse or injecting drug use (IDU)).

## Notifying at risk partners

Once at risk partners have been identified, they are usually contacted by either *Patient referral*; or *Provider referral*. Patient referral is the preferred method and other methods, such as contract referral, are not routinely offered within clinics.

All located partners are then invited to attend a GUM clinic where they are offered HIV counselling and testing. They may choose not to return to the same clinic where the index patient was seen. These methods are voluntary, confidential and provided within the context of comprehensive HIV and STD prevention, care and support programmes.<sup>23,24</sup> Specific roles and responsibilities for counselling and notifying partners are unclear and there is tremendous variation in practice across the country.

**Table 3.** Distribution of responsibilities in the process of HIV partner notification within GUM Clinics.<sup>25</sup>

	Clinic Doctors	Health Advisers	The Patient	Other persons
1. Among clinics where HIV partner notification is routinely discussed with newly diagnosed patients, who usually initiates the discussion?*	27/54 (50%)	42/54 (78%)	3/56 (6%)	3/56 (6%)
2. Who is responsible for ensuring that contacts of newly diagnosed HIV patients have been notified?*	14/59 (24%)	43/59 (73%)	19/59 (42%)	0%
3. Who is responsible for notifying the contacts of newly diagnosed HIV patients?*	5/58 (9%)	29/58 (50%)	49/58 (85%)	0%
4. Who is responsible for documenting the outcome of HIV partner notification in patients' case notes?*	10/56 (18%)	39/56 (69%)	(0%)	7/56 (13%)

\* No statistically significant association with clinic location, participation in the HIV PN Project, clinic size or number of HIV patients seen.

\*\* 100% of respondents from London stated that the patient was one of those primarily responsible for notification, compared with 79% of clinics outside of London.

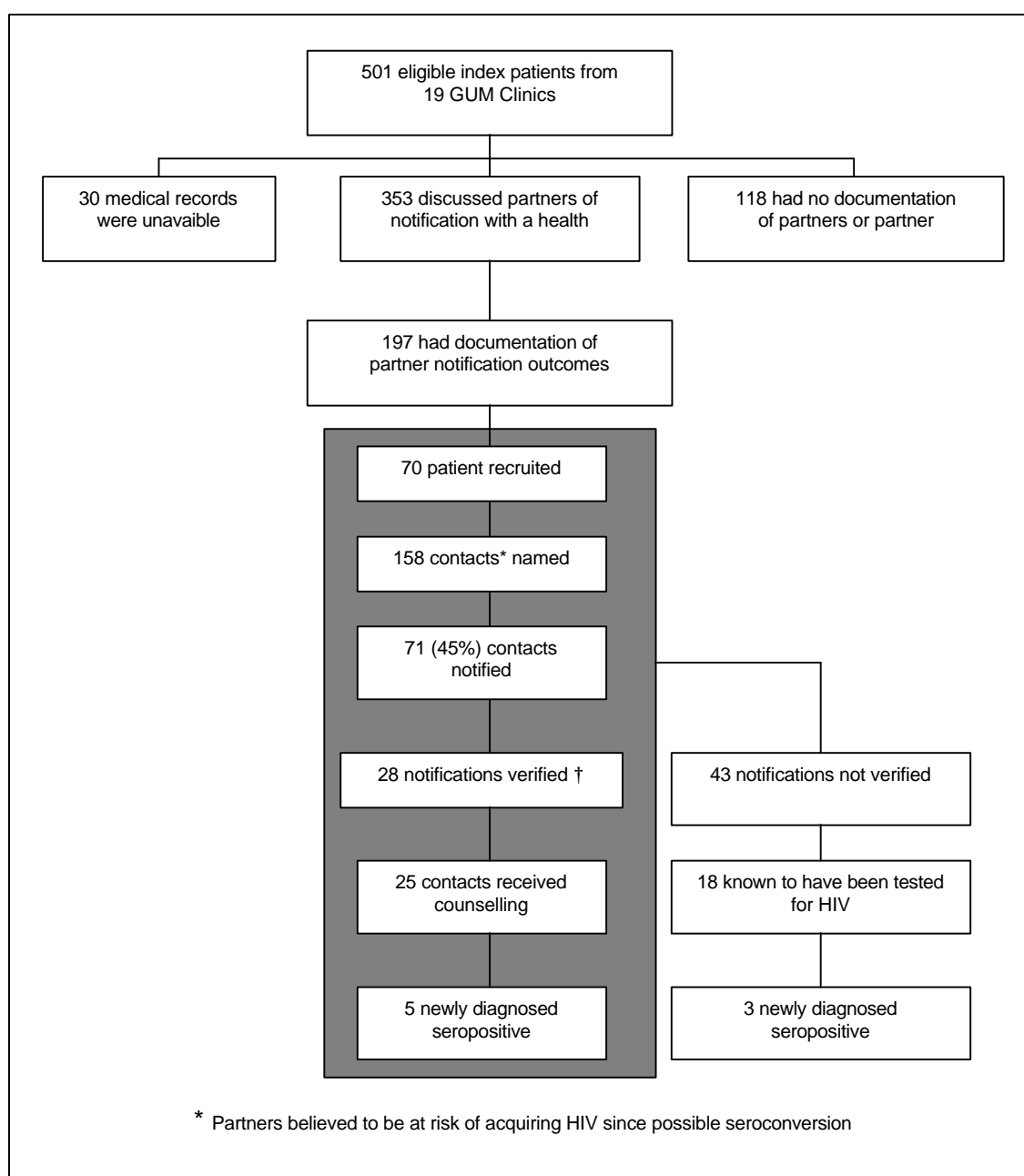
## CURRENT MODEL FOR HIV PARTNER NOTIFICATION IN ENGLAND AND WALES

Step	Time	Event	Action		Advantages	Limitations
1.	Day 1	Patient attends clinic requesting HIV test	Pre-test counselling which covers reasons for testing, risk behaviours, risk assessment, what happens if HIV positive result, support systems, partner notification and the HIV testing procedures	Dr. / HA	<ul style="list-style-type: none"> <li>Open access GUM clinics</li> <li>HIV testing free</li> <li>Same day testing increasingly available</li> <li>Pretest counselling</li> </ul>	<ul style="list-style-type: none"> <li>Many low-risk individuals test and retest</li> <li>Not necessarily those at highest risk testing</li> <li>Some patients do not inform family or friends about decision to test</li> <li>Patient may seek HIV test in an ante-natal clinic, GP surgery or increasingly with home testing kits</li> </ul>
2.	Day 8	Patient returns for HIV test result	HIV test result given	Dr. / HA	<ul style="list-style-type: none"> <li>Trained professionals on hand</li> <li>Results given in person</li> <li>No results given by phone</li> <li>Able to deal with any emergencies</li> </ul>	<ul style="list-style-type: none"> <li>Delay in receiving result may result in increased anxiety about a test result</li> <li>Patients may think that obtaining result from a Dr. means that they are HIV positive</li> </ul>
3.	Day 8	Patient diagnosed HIV negative	Counselling on safer sex, condom use, retesting	Dr. / HA	<ul style="list-style-type: none"> <li>Safer sex messages reinforced</li> </ul>	<ul style="list-style-type: none"> <li>Patient relapses to unsafe behaviour if they are reassured by a negative result</li> </ul>
4.	Day 8	Patient diagnosed HIV positive	Emotional support and counselling	HA	<ul style="list-style-type: none"> <li>Professional support available</li> <li>Can discuss ways of informing partners and friends</li> <li>Able to reinforce treatment options</li> </ul>	<ul style="list-style-type: none"> <li>Negative reactions to HIV test result</li> <li>Patient requires intensive emotional support and counselling</li> </ul>
5.	Day 8 - Week 6	Health Adviser initiates partner notification discussion	Defines notification period and persons at risk through sexual intercourse, IDU, vertical transmission, locating partners, patient and provider referral	HA	<ul style="list-style-type: none"> <li>Patient defines when ready to discuss partner notification.</li> <li>Health adviser responsive to patient's needs</li> </ul>	<ul style="list-style-type: none"> <li>Patient may not feel ready to notify partners</li> <li>Patient refuses to notify partners</li> <li>Patient does not return to clinic</li> <li>Patient transfers to larger/ better clinic</li> <li>No legal duty to inform partners</li> <li>HA does not initiate PN process</li> <li>Wide variation in time between diagnosis and notification of partners</li> </ul>
6.	Day 8 - Week 6	Partner seen in clinic	Seen by health professional. Risk assessment done, counselling, HIV pretest counselling (see Step 1)	Dr. / HA	<ul style="list-style-type: none"> <li>Partners have opportunity to discuss transmission risk and HIV testing (see also Step 1)</li> </ul>	<ul style="list-style-type: none"> <li>Partner is emotionally distressed</li> <li>Risk of harm/ violence to the index patient</li> <li>Partner may go to another clinic therefore outcome information lost</li> </ul>

## OUTCOMES. HIV PARTNER NOTIFICATION IN THE UK

To date, there has been only one national evaluation of the effectiveness of HIV partner notification in GUM clinics. The HIV partner notification project<sup>26</sup> (The HIV PN project) was funded by the DoH to evaluate the degree to which partner notification could succeed in identifying and locating people unaware of their increased risk of HIV infection and the resources (health adviser time and costs) required to do so.

Undertaken in 19 GUM clinics, this study had many limitations, chief of which was the low recruitment rate (14% of eligible patients). Of 501 eligible patients, 353 (70%) discussed partners with the health adviser. Only 197 (40%) had casenote documentation of PN outcomes. The most common reasons given by health advisers for not doing partner notification were patient being too emotionally distressed (23%) or patient not returning to the clinic (21%). Five newly diagnosed infections were obtained through PN, none of whom were previously aware of their HIV risk.



## ETHICAL ISSUES

The mid to late eighties were characterised by intense ethical and political debates about the appropriateness and application of partner notification for HIV infection. In England, the debates were often related to press revelations about “innocent” individuals who were unknowingly infected by their sexual partners. This highlighted the vulnerability of the general population to HIV as well as called upon the Department of Health and then government to bring into effect tough legislation.

The ethical questions were many: do infected patients have a moral duty to inform sexual or drug injecting contacts of their exposure risk?<sup>27,28,29</sup> Does the health care worker’s relationship with the index patient take priority over the obligation to protect others from the patient’s infection? Just how important is an individual’s right to know that he or she may be at risk? Some critics have argued that the ethical debate was ultimately destructive and erroneously shifted the perception of partner notification from the supportive tradition of contact tracing to the more threatening stance of having a “moral or legal duty to inform”.<sup>30</sup>

Much of the ethical debate has also centred around the appropriateness of applying partner notification to HIV infection based on the experiences with STD partner notification. Many have argued that this is inappropriate, as HIV infection imposes many special considerations:

**1. *Most STDs are curable. There is as yet no cure for HIV infection***

Many have argued that the process of identifying and locating partners is unethical if no effective therapy can be given. This however ignores the other benefits to the contact as discussed in Table 1.

**2. *STD treatment offers clear benefit. The benefits of early HIV diagnosis to the unsuspecting partner have not always been clear.***

Emerging evidence suggests that early antiretroviral therapy can delay progression to AIDS<sup>31,32</sup> and reduce the incidence of opportunistic infections.<sup>31</sup>

**3. *STDs have defined incubation and infectious periods. For HIV infection this is unclear.***

The variable incubation period (between infection and advanced HIV disease) makes it difficult to define how far back in time partners should be notified.<sup>33,34</sup> The long infectious period means that partner notification would need to be repeated over time as partnerships disrupt and new relationships are formed.

**4. *Many STD are symptomatic. HIV has (in most cases) an asymptomatic early phase.***

During the early phase of infection, many individuals are asymptomatic and other interventions may be more appropriate to identify these individuals (e.g. health promotion with high-risk groups).



## **5. *HIV infection is still associated with tremendous stigma.***

Critics have argued that PN programmes will drive at risk individuals “underground” resulting in decreased testing and a deterioration of trust between index patients and health care providers.<sup>33,35</sup>

## **PRACTICAL ISSUES**

### ***Difficulties in implementing HIV partner notification programmes***

Despite international and national recommendations, the implementation of HIV partner notification programmes has been poor.<sup>10,36</sup> This reflects in part, the special requirements imposed on the process by HIV infection. From the healthcare workers' perspective, concerns over the ethics of the strategy, adverse outcomes and acceptability to patients have also contributed.

### ***Concerns regarding its adverse effects***

Concerns regarding the potential adverse effects of HIV partner notification have made some health care workers reluctant to implement the strategy. Domestic violence after partner notification, especially among women from lower socio-economic and ethnic minority backgrounds, has been documented.<sup>21,37,38</sup> Other potential adverse effects of partner notification include stress, stigmatisation and discrimination among notified contacts.<sup>39</sup> Loss of confidentiality through identification of the index patient is often of particular concern when dealing with small or enclosed communities. The likelihood of violence and other adverse outcomes has not been quantified, though it appears to be relatively low.

### ***Acceptability to patients and contacts.***

Anecdotal reports suggest that health care workers concerns regarding the acceptability of partner notification to patients have limited widespread implementation. Current evidence suggests that these concerns may be unfounded. For infected patients, the maintenance of confidentiality appears to be an important determinant in the acceptability. A study of 25 HIV-positive women in New Jersey<sup>40</sup> showed that 68% of them were willing to give the names of their sexual partners to the health-department as long as their (i.e. the index patients') confidentiality was maintained. Only 20% of the women would agree to partner notification if their names were disclosed to the partner.

Notified partners are also likely to give positive feedback about their notification experiences. Jones et al. in South Carolina<sup>41</sup> studied the acceptability of health department notification in an anonymous questionnaire to partners notified of their exposure during the preceding 2 years. Of the 202 partners notified, 132 (65%) were locatable and completed the questionnaire. When asked whether they thought the health department did the right thing in telling them about their exposure, 87% responded yes; when asked whether the health department should continue to notify persons exposed to HIV, 92% agreed.

There have been no published studies concerning the acceptability of HIV partner notification patients or their contacts in the UK.

### ***Acceptability to health care workers***

Very little research has assessed the acceptability of partner notification to health care workers. Keenlyside et al (1991) found that HIV partner notification was discussed with the majority of newly diagnosed HIV patients, though marked variations in attitudes towards PN were noted between health care workers and location of clinics. Allen and Hogg (1993) review of professional roles and responsibilities within GUM clinics found that there was general agreement among professionals that PN should be done for STDs significantly fewer felt that it should be done for HIV infection. Fenton et al (1995) found evidence of change in attitudes towards PN, associated with greater understanding, more experience in the field and the availability of anti-retroviral therapy. Some of the key points raised included:

- Partner notification was an important activity that should be routinely discussed with patients.
- Doubts were expressed concerning the practicalities of HIV PN. When should it be initiated? By whom?
- Partner notification should be offered at an appropriate time in the consultation with each patient.
- A few clinicians felt that HIV partner notification was entirely the patient's responsibility.
- Consultants were concerned about client confidentiality. This was especially among refugees or certain migrant ethnic groups, who may view partner notification as an intrusive, state sponsored exercise.
- Consultants felt that many issues on HIV partner notification needed to be discussed between the various professional groups and within the GUM specialty.

### ***The impact of new technologies***

Any model of partner notification should be built upon existing frameworks for STI diagnosis and treatment facilities, encompass the principles of confidential and non-judgmental care and be acceptable and appropriate to those individuals using the service. Increasingly, partner notification services must also respond to changes in technology which can facilitate the diagnosis and management of HIV infection. The availability of at home testing kits; testing via telephone; urinary and salivary assays will impact on the ability to provide effective partner notification services. The advantages to the individual are immediately obvious: greater flexibility and acceptability, anonymity and the possibility of obtaining rapid diagnoses. However, legitimate concerns have been raised about people testing in isolation; lack of support; the absence of pre or post test counselling. It remains to be seen how these technologies will influence current patterns of HIV testing.

Very little has been written about how these technologies may be used to enhance partner notification. For example, can the acceptability to contacts be improved by using non-invasive diagnostic techniques? Can non-invasive tests facilitate notification

investigations of sexual networks? These are only a few of the challenges facing partner notification programmes in the future.

## CONCLUSIONS

In England and Wales, our experience with HIV partner notification over the past 15 years has taught us:

- Concerns about individual rights remain paramount in the national ethos. This has had an enormous influence on the attitudes of the public, health workers and clients towards partner notification and ultimately the success of the strategy.
- Attitudes towards partner notification vary greatly, across and within professional and client groups. It is likely that this has strongly influenced the degree to which PN is locally implemented.
- The availability of effective anti-retroviral therapies have SLOWLY swung the balance of benefit in favour of HIV partner notification over the past three years. Health advisers now feel more empowered to discuss PN issues with patients because they believe that their contacts may truly stand to benefit.
- Over time, much of the ethical debate on HIV partner notification has abated. It is however often rekindled when required by the press, or by the medical fraternity in “difficult” cases.
- The lack of local clinic policies and guidance on HIV partner notification have hindered its widespread implementation and evaluation.
- It is difficult to expect a proactive and effective HIV partner notification programme in the absence of a formalised training for health advisers and STD physicians.
- At a local level, clinical audit and health service contract specifications provide mechanisms for ensuring that programmes are implemented and monitored.
- Reservations about the utility of PN based on the perceived limitations among gay and bisexual men need to be revisited as the heterosexual HIV epidemic develops.

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