

# IMPRESS Health 2 Study: Anglo-French Phase 1 research findings

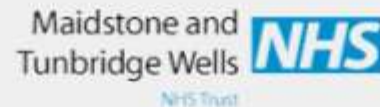
Dr Stephen J. O'Connor: Reader in Cancer, Palliative and End of Life Care,  
Canterbury Christ Church University.

Philippe Lorenzo (IREPS chief investigator, qualitative data collection,  
analysis and reporting, external liaison etc.)

# What is the IMPRESS Health 2 Project?

- A €1million cross channel (Transmanche) Interreg project

In partnership with:



<http://www.impresshealth2.eu/>

## UK research staff

- Dr Stephen O'Connor (chief investigator, qualitative data collection, analysis and reporting, external liaison etc.)
- Sharon Manship (research assistant and deputy project lead, qualitative data collection, analysis and reporting)
- Sarah Keeling Smith (Project administrator/finance)
- Matt Hart (qualitative data collection and analysis)
- Fiona Tudor (transcribing of qualitative data and analysis)
- Professor Stephen Clift (statistical analysis of clinical data)
- Agatha Benyera-Mararike (psychological support for respondents/staff)

# French research staff

- Philippe Lorenzo (IREPS chief investigator, qualitative data collection, analysis and reporting, external liaison etc.)
- H el ene Trouillet (IREPS qualitative data collection, analysis and reporting)
- Professor Jean Luc Schmit (Project lead: CHU Amiens)
- Momar Diouf (CHU Amiens: statistical analysis of clinical data)
- Research team of the Clinical Research Centre CHU Amiens (qualitative data collection )

# Methodology

- A multi-centre, mixed-methods study incorporating statistical (clinical and demographic) data and qualitative (interview) data.

*'When used in combination, both quantitative and qualitative data yield a more complete analysis, and they complement each other.'*

(Creswell et al, 2004 p7)



# Methodology

- A multi-centre, mixed-methods study incorporating statistical (clinical and demographic) data and qualitative (interview) data.

*‘When used in combination, both quantitative and qualitative data yield a more complete analysis, and they complement each other.’*

(Creswell et al, 2004 p7)



- *Phase 1: Research phase  
October 2013 – March 2014*
- *Phase 2: Implementation phase  
April 2014 – December 2014*
- *Phase 3: Evaluation phase  
January 2015 – March 2015*

# Methodology

- A multi-centre, mixed-methods study incorporating statistical (clinical and demographic) data and qualitative (interview) data.

*'When used in combination, both quantitative and qualitative data yield a more complete analysis, and they complement each other.'*

(Creswell et al, 2004 p7)



- **Phase 1: Research phase  
October 2013 – March 2014**
- **Phase 2: Implementation phase  
April 2014 – December 2014**
- **Phase 3: Evaluation phase  
January 2015 – March 2015**

# Aims of the research phase of the study

To identify reasons or statistical correlates explaining the continued late diagnosis of so many people in Kent, Medway, Amiens and Creil (in France) with HIV. The following objectives were therefore set:

- Review clinical data of patients diagnosed with HIV for five years (December 2008 to December 2013) to identify variables correlated with late diagnosis such as gender, age, occupation etc.
- Recruit and interview a target number of HIV positive patients diagnosed in the same five year period to elicit their knowledge, understanding, views, and experiences of HIV testing and reasons for not seeking a test earlier
- Recruit and interview a target number of healthcare professionals to elicit their knowledge, understanding, views, and personal experiences of HIV testing, and potential barriers to testing
- Make recommendations for a joint programme of clinical, health education, social media and professional education interventions to encourage earlier testing and diagnosis of HIV in both countries which would help to increase the uptake of early HIV testing in both countries.



# Data collected in the UK

- Quantitative
  - review of clinical data of 242 patients diagnosed as HIV+ in last five years in four Trusts in Kent and Medway
- Qualitative
  - 37 semi-structured interviews with patients
  - 16 interviews with health or social care professionals
- Research centres used
  - Medway NHS Foundation Trust
  - Maidstone and Tunbridge Wells NHS Trust
  - Kent Community Health Foundation Trust (together with East Kent Hospitals University NHS Foundation Trust)

# Data collected in France

- Quantitative
  - review of clinical data of 166 patients diagnosed as HIV+ in last five years in the two main hospitals (Amiens and Creil)
- Qualitative
  - 45 semi-structured interviews with patients
  - 51 semi-structured GP interviews
- Research centres used
  - Centre Hospitalier Universitaire Amiens Picardie
  - Groupe Hospitalier Public du Sud de l'Oise (Creil)

## Findings from UK clinical (quantitative) data

- 145 (60.4%) of patients had CD4 counts on diagnosis of 350 or less (i.e. diagnosed late), and 39.6% had CD4 counts over 351 (early diagnosis)
- No significant difference in the levels of late diagnosis found between health trusts or areas involved in the study
- Patients' ages ranged from 19 to 81 years with a mean age of 40 years
- Patients diagnosed late were four years older on average than those diagnosed early (statistically significant)
- Approximately two thirds of the sample were men, but no gender difference is apparent in levels of late diagnosis
- Ethnically diverse sample (56% White British/Irish, 30% Black, 4% Asian, 1% Mixed and 8% Other)
- Late diagnosis was more common in ethnic minority groups (70%) compared with the White group (53%) (statistically significant).

## Findings from UK clinical data

- Patients born outside the UK were more likely to be diagnosed late (marginally statistically significant)
- Most frequent categories were heterosexual and MSM, with small numbers of people in the IDU and 'other' categories
- Most common place of testing was the GUM clinic, followed by hospital following admission due to illness
- Limited testing also took place in the context of ante-natal screening, and in 41 cases, initial test took place elsewhere
- Very high levels of late diagnosis were found for patients admitted to hospital on account of illness (89%) compared with other settings (range from 49.6-57.1%).

# Findings from French clinical data

- Late diagnosis of HIV infection is substantial across Amiens and Creil.
- One hundred and sixty six patient records were examined and of these eighty three (50.0%) had CD4 counts on diagnosis of 350 or less.
- No significant difference in the levels of late diagnosis was found across the health trusts involved in this survey.
- HIV is no respecter of age. Patients at first diagnosis ranged in age from 17 to 71, with a mean age of 37.
- Patients diagnosed late were six years older on average than those diagnosed early. This difference is statistically significant.
- Approximately one half of the sample is men, but no gender difference is apparent in levels of late diagnosis.

## Findings from French clinical data

- Patients born outside France were also more likely to be diagnosed late, although this difference was statistically significant.
- The most frequent categories are heterosexual and MSM, with small numbers of people in the IDU and 'other' categories.
- The profile of transmission groups also varies markedly by country of birth. The largest group among French born patients is heterosexual (56 %), whereas for the Rest of the World, 88% of patients are heterosexual (88 %).
- 37% of French born patients were in the MSM group, whereas only 5% were MSM group in the 'rest of the World' group.
- There is no clear association between late diagnosis and transmission group: 53% of the heterosexual group were diagnosed late and 43% of MSMs. The difference is not statistically significant however.

## CD4 Status on diagnosis (both countries)

			CD4 count ≤350	CD4 count >350	Total
UK	Maidstone and Tunbridge Wells	Number	42	23	65
		Percentage	64.6%	35.4%	100.0%
	Kent Community Health NHS Trust	Number	66	53	119
		Percentage	55.5%	44.5%	100.0%
	Medway	Number	37	19	56
		Percentage	66.1%	33.9%	100.0%
	UK Totals	Number	145	95	240
		Percentage	60.4%	39.6%	100.0%
France	Amiens	Number	49	47	96
		Percentage	51.0%	49.0%	100.0%
	Creil	Number	34	36	70
		Percentage	48.6%	51.4%	100.0%
	France Totals		83	83	166
			50.0%	50.0%	100.0%

## CD4 Status on diagnosis (both countries)

			CD4 count ≤350	CD4 count >350	Total
UK	Maidstone and Tunbridge Wells	Number	42	23	65
		Percentage	64.6%	35.4%	100.0%
	Kent Community Health NHS Trust	Number	66	53	119
		Percentage	55.5%	44.5%	100.0%
	Medway	Number	37	19	56
		Percentage	66.1%	33.9%	100.0%
	UK Totals	Number	145	95	240
	Percentage	60.4%	39.6%	100.0%	
France	Amiens	Number	49	47	96
		Percentage	51.0%	49.0%	100.0%
	Creil	Number	34	36	70
		Percentage	48.6%	51.4%	100.0%
	France Totals	Number	83	83	166
		Percentage	50.0%	50.0%	100.0%



## Place of birth and CD4 count (both countries)

			CD4 count ≤350	CD4 count >350	Total
UK	UK born	Number	71	62	133
		Percentage	53.4%	46.6%	100.0%
	Rest of world	Number	74	32	106
		Percentage	69.8%	30.2%	100.0%
	UK Totals	Number	<b>145</b>	<b>94</b>	<b>239</b>
		Percentage	<b>60.7%</b>	<b>39.3%</b>	<b>100.0%</b>
France	French born	Number	33	47	80
		Percentage	41.3%	58.7%	100.0%
	Rest of world	Number	50	35	85
		Percentage	58.8%	41.2%	100.0%
	France Totals	Number	<b>83</b>	<b>82</b>	<b>165</b>
		Percentage	<b>50.3%</b>	<b>49.7%</b>	<b>100.0%</b>

## Place of birth and CD4 count (both countries)

			CD4 count ≤350	CD4 count >350	Total
UK	UK born	Number	71	62	133
		Percentage	53.4%	46.6%	100.0%
	Rest of world	Number	74	32	106
		Percentage	69.8%	30.2%	100.0%
	UK Totals	Number	145	94	239
		Percentage	60.7%	39.3%	100.0%
France	French born	Number	33	47	80
		Percentage	41.3%	58.7%	100.0%
	Rest of world	Number	50	35	85
		Percentage	58.8%	41.2%	100.0%
	France Totals	Number	83	82	165
		Percentage	50.3%	49.7%	100.0%

## Likely transmission routes (both countries)

			CD4 count ≤350	CD4 count >350	Total
UK	Men who have sex with men	Number	44	44	88
		Percentage	50.0%	50.0%	100.0%
	Intravenous drug users	Number	4	1	5
		Percentage	80.0%	20.0%	100.0%
	Heterosexual	Number	87	48	135
		Percentage	64.4%	35.6%	100%
	Other	Number	7	1	8
		Percentage	87.5%	12.5%	100%
	UK Totals	Number	142	94	236
		Percentage	60.2%	39.8%	100.0%
France	Men who have sex with men	Number	15	20	35
		Percentage	42.9%	57.1%	100%
	Intravenous drug users	Number	0	1	1
		Percentage	0.00	100.0%	100%
	Heterosexual	Number	63	56	119
		Percentage	52.9%	47.1%	100%
	Other	Number	4	6	10
		Percentage	40.0%	60.0%	100%
	France Totals	Number	82	83	165
		Percentage	49.7%	50.3%	100.0%

- MSMs - lowest proportion of late diagnoses compared to all other transmission groups
- The percentage of MSMs diagnosed late higher in the UK than in France (50% v 42.9%)
- Percentage of heterosexual patients diagnosed late was also much higher in the UK (64.4% versus 52.9%)
- Differences in early and late diagnoses in both these groups are statistically significant even when missing data is accounted for.

# Patient interview sample in the UK

- Patient respondents
  - 29 male (13 MSM, 11 heterosexual, 3 bisexual, 2 undisclosed)
  - 8 female (all heterosexual)
  - 16 early presenters:
    - 12 male (4 heterosexual, 7 MSM, 1 undisclosed)
    - 4 female - heterosexual
  - 21 late presenters
    - 17 male (7 heterosexual, 6 MSM, 3 bisexual, 1 undisclosed)
    - 4 female - heterosexual

# Healthcare professional sample in the UK

- 5 General Practitioners
- 3 Specialist Social Workers
- 2 Genitourinary Consultants
- 1 Clinical Nurse Specialist
- 1 Sexual Health Nurse
- 1 Specialist HIV Pharmacist
- 1 Nephrology Consultant
- 1 Gastroenterologist
- 1 Obstetrics and Gynaecology Consultant

# Healthcare professional sample in the UK

- 5 General Practitioners
- 3 Specialist Social Workers
- 2 Genitourinary Consultants
- 1 Clinical Nurse Specialist
- 1 Sexual Health Nurse
- 1 Specialist HIV Pharmacist
- 1 Nephrology Consultant
- 1 Gastroenterologist
- 1 Obstetrics and Gynaecology Consultant



# Findings from UK patient interviews

- Patient satisfaction
  - Extremely happy with care received in GUM/Sexual Health clinics
  - Mixed experiences of acute hospital care
  - Quite critical of care received in primary care – especially GPs

*'I don't think their [GPs] knowledge of HIV and the way it's transmitted, and the symptoms, and also how they deal with someone when they've contracted it is particularly good at this point in time.'*

- Most surprised that routine testing/screening not more common and felt these should be 'normalised' and more routine
- Most had limited knowledge about the benefits of early testing and lacked access to information – especially heterosexuals

# Findings from UK patient interviews

- Stigma, fear and anxiety prevalent
- Concerns about impact on lifespan, employment and relationships (including how to break the news to a partner(s), friends and family) were common
- Financial and insurance concerns were a common cause for people to delay seeking an immediate test
- Stigma attached to GUM/sexual health clinics also deterred some (especially older, females) from seeking testing
- Most respondents, and all older respondents, recalled the graphic public health campaigns of the 1980s and 1990s in relation to HIV/AIDS but thought these accentuated the notion of HIV being a 'gay disease'

*'...It was all... 'if you've got it, that's it. You're going to be dead within so many months' or whatever; and I think that was the stigma with it.'*



# Findings from French patient interviews

- Lack of precise knowledge concerning modes of transmission of the virus.
- Reasons associated with late diagnosis:
  - Feeling of not being at risk for HIV contamination
  - Fear for stigma, cultural reasons
- On diagnosis of a positive HIV status:
  - Surprise
  - Fear (fear of death?, fears for future?)
  - Regard d'autrui
  - Stigma, or feeling of being stigmatised
  - Need to control one's behaviour in front of others except a few very close friends or relatives.

# Findings from UK health professional interviews

- Areas of poor practice and a general lack of HIV awareness and training amongst GPs
- Several GPs intimated that HIV is simply *'not on the radar'* of their colleagues
- HIV considered to primarily the remit of GUM/sexual health clinics
- Two respondents suggested that GPs don't get paid to think about HIV as they are with other chronic conditions such as diabetes and obesity
- Misunderstanding about the 'statutory' need for pre-test counselling constrained many GPs from raising the topic as worried about time implications
- Some other medics e.g. surgeons in acute areas also felt that HIV testing was not *'within their remit'* – but thought they should be informed of the patient's status if positive!

# Findings from French GP interviews

- Lack of interest.
- Very few GPs take care of patients with HIV so no impetus for updating themselves or seeking continuing professional development.
- Not routinely screening patients except in standard situations (pregnancy, other STD etc.)
- Patients were usually the ones initiating a request for a test most of the time.
- Difficulties in giving a positive result: *'not familiar with the situation', 'lack of preparedness'*
- Underlying problem: *'how to talk about sexual risk behaviours - especially in elderly patients'*.

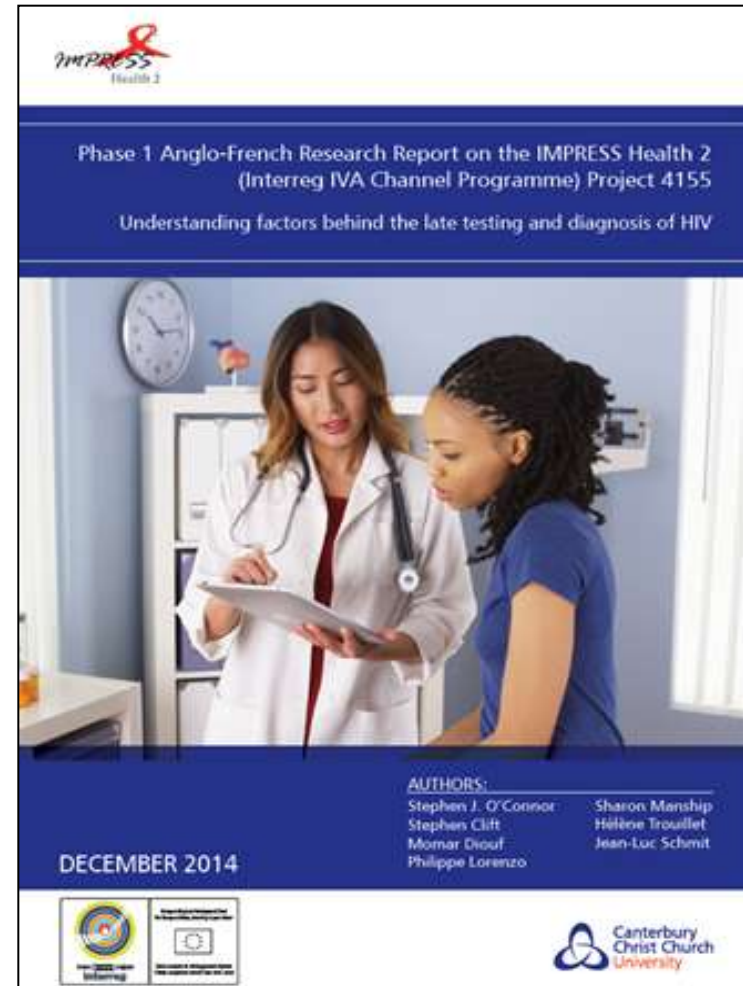
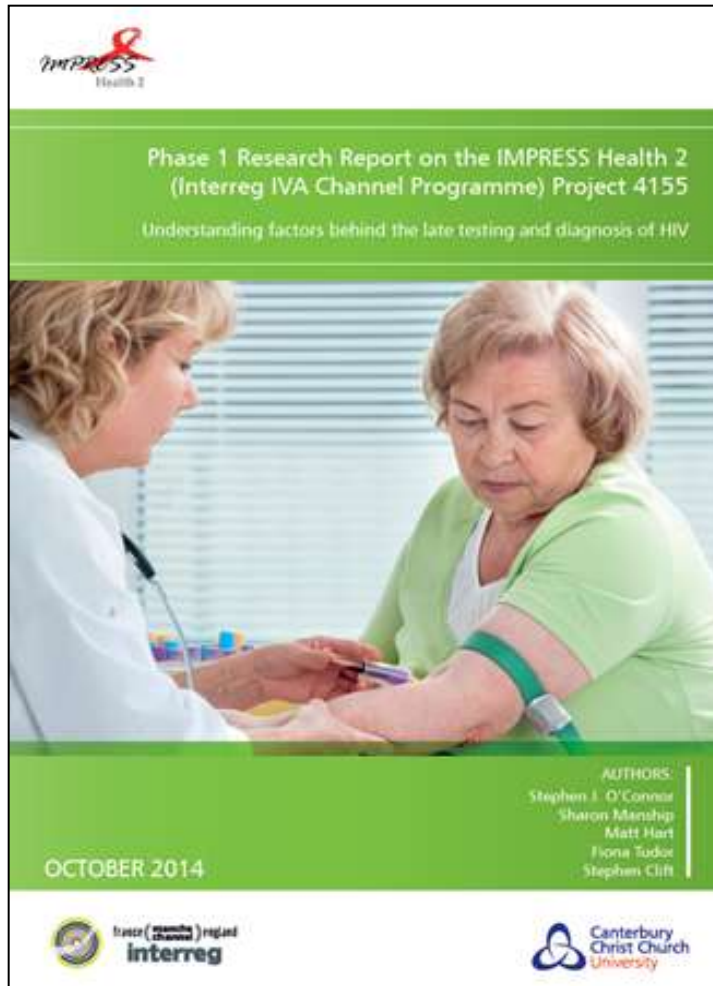
# Conclusions and recommendations

- Lack of engagement in HIV surveillance, testing and diagnosis within primary healthcare needs addressing
- Need to raise awareness of the need for early HIV testing amongst general public and HCPs (updated messages to challenge erroneous assumptions about risk and causation)
- Clinical areas would benefit from having clear policies and procedures in place to identify those in need of an HIV test and a means of immediate referral for further support
- Better HIV surveillance and improved rates of early testing could be achieved by relatively simple changes to organisational processes (automatic HIV test in people sent for STD screening etc. aide memoires for patients with frequent indicative health problems etc.)

# Conclusions and recommendations

- Determine whether services could be delivered differently in some areas
- Increased stakeholder engagement and liason with PH bodies in local authorities, charity sector etc.
- Development of pilot outreach projects (e.g. 'blue bus' roadshow)
- Increased accessibility to HIV testing in non-stigmatising locations including workplace testing, clubs, pubs, football grounds etc.
- Social media and health education campaigns jointly funded and supported by NHS, charitable, and local authorities
- Efforts could be piloted around National HIV Testing Week (last week of November) in the run up to World AIDS Day.
- *All of these formed the basis for the phase 2 intervention study*

# More information on phase 1 (research phase)



<http://www.impresshealth2.eu/>