



Integrate

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

WP4 - Policy development and sustainability

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WP4 - Policy development and sustainability

Overall objective:

- policy development and sustainability of JA deliverables and results at the national level through a package of activities, including country-specific recommendations.
- Integration of patient experience measures of testing and linkage to care into countries own monitoring systems for quality improvement.

Specific Objectives

- Obj1: to develop a **sustainability plan** *for the pilot actions*;
- Obj2: to develop a **roadmap** on how to integrate deliverables and results of the pilot actions into national policies and support review of national medical guidelines *in the pilot countries*;
- Obj3: to provide policy-makers with proof of concept and **practical guides for integrating patient experience** into national monitoring;

Deliverables

- **D4.1 : Sustainability plan [M12]**

Development of a sustainability plan for the Joint Action, including description of the deliverables, review and assessment activities and a plan for the integration of deliverables into national policies.

- **D4.2 : Report/Roadmap on results of pilot activities [M24]**

Based on the sustainability plan, development of a roadmap on how to integrate concretely deliverables and results of the Joint Action into national policies and action plans and support the review of the national medical specialty guidelines. [M12, M18, M24]

- **D4.3 : Patient experience toolkit [M32]**

Toolkit for countries on how to capture patient experiences, including a checklist, list of key indicators, table of validated indicators, process diagram, and examples of best practice.

Topics, Pilots, Countries and WP links

- 1. Provider initiated testing – specialty guideline review**
Serbia, Romania and Lithuania (linked to WP5 activity)
- 2. HIV home-testing/sampling**
Lithuania, Italy and Ireland (linked to WP5 activity)
- 3. Integration of testing data into national systems, including CBVCT**
Serbia, Spain, Slovakia, Poland, Estonia and Slovenia (linked to WP5 and 6)
- 4. Novel prevention strategies and partner notification**
Romania, Greece, Italy, Ireland and Bulgaria (linked to WP7)
- 5. Demonstration projects to pilot a patient experience survey for HIV, STIs, hepatitis and/or TB infection**
Serbia, Romania, Spain and Croatia (Obj3).

Obj1 – Sustainability plan (MS14/M12)

It includes:

- **Description of the deliverable/results that are recommended to be further developed**, consolidated or maintained by participating countries;
- **Stakeholder consultation in pilot countries to identify key actors** (institutions and bodies) responsible for health policy planning, existing strategies and ongoing policy developments – *MS12/M8*
- **Short countries health systems and health policies profiles** and barriers to integration/sustainability;
- **Review of specialty guidelines and recommendations** for HIV, hepatitis, STIs and TB testing and linkage to care;
- **Overview of the cost-effectiveness** of piloted activities based on existing studies and publications (to support national stakeholder) – *MS13/M12*
- **Tasks of partners in the plan** for facilitation of integration into national policies.

Obj2 – Roadmap (MS15/M18)

Roadmap for **concrete** policy change, action plan and specialty guidelines review.

- **Stakeholder consultation with identified key actors responsible for health policy** planning in order to discuss the sustainability plan and assess/agree on the interest and feasibility of a more concrete roadmap for the integration of the piloted actions in the local policies
- It will include **general principles and country-specific recommendations for activities** on the international and national levels that need to be undertaken in selected pilot countries to secure sustainability of pilot actions that proved successful.
- Each pilot country will receive **specific recommendations in a dedicated and extractable section of the roadmap.**

Next steps (first year)

Obj1 - Sustainability plan:

- **Short profiles of the health systems** and health policies relevant for the integration of pilot activities (*WP4 partners according to their piloting topic*)
- Indicator guided testing- medical **speciality guideline review** (*WP4 partners in Serbia?, Romania and Lithuania*)
- Integration of CBVCT in **national surveillance** and M&E systems-policy, recommendation and guidance **review** (*WP4 partners in Serbia, Spain, Slovakia, Poland, Estonia and Slovenia*)
- **Stakeholder consultation** identifying relevant key actors (*WP4 partners according to their piloting topic*)
- **Overview of the cost-effectiveness** of piloted activities (*WP4 leader and co-leader + other WPs leaders?*)

Obj3 - Integrating patient experience into national monitoring

- Meeting report from **stakeholder consultation**



Activities under WP 4.3: Patient experience surveys



Led by REGIONH/CHIP (Jeffrey Lazarus) and
PHE (Valerie Delpech/Meaghan Kall)

WP 4.3 Aim & Objectives

Aim:

- ▶ To develop and implement pilot actions for the monitoring of patient experience in testing and linkage to care among people newly diagnosed and living with HIV, hepatitis and/or TB to support potential uptake of best practice and evidence-based policy recommendations

Objectives:

1. To develop a toolkit for implementing a **repeatable**, cross-sectional patient experience survey that is **feasible** to implement, **acceptable** to patients, and requires **minimal resources** to run
2. To provide preliminary **survey estimates** on **barriers and determinants** of late diagnosis and delayed linkage to care



WP 4.3 Activities

- ▶ Stakeholder consultation to identify key methodological considerations to capture and monitor the experiences of testing and linkage to care of people with HIV, STIs, hepatitis and/or TB in their country. **(Meeting report: M9)**
 - ▶ Coordination of demonstration projects to pilot a patient experience survey for HIV, STIs, hepatitis and/or TB infection in the following countries: Croatia, Romania, Serbia (TBC), Spain. **(Protocol: M12, Complete pilots: M32)**
 - ▶ Develop a toolkit aimed at policy-makers to facilitate countries to create their own system for monitoring patient experience in testing and linkage to care, including a checklist, table of validated indicators, process diagram, and examples of best practice. **(Patient experience toolkit: M32)**
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Patient experience survey aims

To understand barriers to testing

- Access to testing
- Reasons for testing
- Reasons for delayed or avoidance of testing
- Testing frequency (ever tested, most recent negative)

To understand barriers to linkage to care

- Time from test to entry
- Reasons for delay or avoidance of accessing care
- Diagnosis setting
- Access to care

To understand determinants of late diagnosis and linkage to care

- Socioeconomic and demographic factors
 - Quality of life
 - Stigma and discrimination
 - Engagement with different types of services
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Primary Q's: Barriers to testing and care

- ▶ **Topic areas for questions informed by:**
 - ▶ ECDC systematic review on barriers to HIV testing
 - ▶ OptTEST HIV linkage to care: systematic review, TeSSY data analysis, country survey
 - ▶ Review of existing (validated) survey questions/ instruments on barriers to HIV/HCV/TB/STIs testing and care
- ▶ **Survey questions and methods will be presented & discussed at stakeholder consultation meeting in M6**



Example Secondary Q's: Sociodemographics

A2 How do you identify your gender?

Woman (including trans women)

Sex

Man (including trans men)

Prefer not to say

A3 Is this the same gender as you were assigned at birth?

Yes

Gender identity

A4 In what country were you born?

Country of birth

A5 To which of these groups do you consider yourself belonging?

A. White

British

Irish

Any other White background

B. Black or Black British

African

Caribbean

Any other Black background

C. Mixed/multiple ethnic groups

White and Black Caribbean

White and Black African

White and Asian

Any other mixed background

D. Asian/Asian British

Indian

Pakistani

Bangladeshi

Chinese

Any other Asian background

E. Other ethnic groups

Arab

Hispanic/Latino

Any other ethnic group

Ethnicity

110 In the last YEAR, what was your **TOTAL** household income before tax?

Household income is the combined income of everyone in the household, from all sources, before tax. This includes earnings from employment or self-employment, benefits, pensions, other sources such as interest from savings.

Annual	Weekly
<input type="checkbox"/> Under £5,000	<input type="checkbox"/> Under £100
<input type="checkbox"/> £5,000 – £9,999	<input type="checkbox"/> £100 – £199
<input type="checkbox"/> £10,000 – £19,999	<input type="checkbox"/> £200 – £399
<input type="checkbox"/> £20,000 – £29,999	<input type="checkbox"/> £400 – £599
<input type="checkbox"/> £30,000 – £39,999	<input type="checkbox"/> £600 – £799
<input type="checkbox"/> £40,000 – £49,999	<input type="checkbox"/> £800 – £999
<input type="checkbox"/> £50,000 – £59,999	<input type="checkbox"/> £1,000 – £1,199
<input type="checkbox"/> £60,000 – £69,999	<input type="checkbox"/> £1,200 – £1,399
<input type="checkbox"/> £70,000 – £89,999	<input type="checkbox"/> £1,400 – £1,799
<input type="checkbox"/> £90,000 – £109,999	<input type="checkbox"/> £1,800 – £2,199
<input type="checkbox"/> £110,000 – £129,999	<input type="checkbox"/> £2,200 – £2,599
<input type="checkbox"/> £130,000 – £149,999	<input type="checkbox"/> £2,600 – £2,999
<input type="checkbox"/> £150,000 or more	<input type="checkbox"/> £3,000 or more
<input type="checkbox"/> Don't know	<input type="checkbox"/> Don't know

14 What is the highest level of education that you have completed?

Education

No formal qualifications

City and Guilds/Equivalent

Postgraduate degree

Other (please specify)

Qualifications at age 18 (A-levels, AS-levels, high school diploma)

City and Guilds/Equivalent

Other (please specify)

15 What is your current work situation?

Tick all that apply

Employed or self-employed FULL-TIME (at least 30 hours per week)

Long-term sick/disabled (for 3 months or more)

Temporarily sick/disabled (less than 3 months)

Employment

Part-time (less than 30 hours per week)

Retired

Full time student/education/training

Other (please specify)

Unemployed

11 Which of the following best describes how you think of yourself?

Straight/Heterosexual

Gay or Lesbian/Homosexual

Sexuality

Other

Prefer not to say

12 What is your religion?

None/Atheist/Agnostic

Jewish

Religion

Sikh

Christian

Buddhist

Other

Hindu

Prefer not to say

16 Where do you currently live?

Own or purchasing house or flat

Sheltered accommodation/retirement housing

Renting (privately owned)

Residential care home

Housing

Temporary accommodation (hotel, shelter, bed & breakfast)

Homeless (rent-free provided by friends, family, etc)

Homeless (other)

Other (please specify)

Example Secondary Q's: Stigma & Patient Experience

following in a healthcare setting?

✓ Healthcare avoidance

	In the year	Yes, more than a year ago	No
Been worried that you would be treated differently to other patients?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

✓ Healthcare discrimination

	In the year	Yes, more than a year ago	No
Avoided seeking healthcare when you needed it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Felt that you were refused healthcare or delayed a treatment or medical procedure?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

✓ Healthcare confidentiality

... tell us about when ... of your HIV status.

D5 Does your GP know your HIV status?

- Yes
 NO → PLEASE GO TO QUESTION **D7**

B3 Apart from health care staff, who have you told that you have HIV?

Tick all that apply

✓ Disclosure

- ... (e.g. family, friends, neighbours, co-workers, etc.)
- Sexual partner(s) Nobody

✓ Patient satisfaction

0	1	2	3	4	5	6	7	8	9	10

D10 Here are some statements about your experience with your HIV clinic. Please tick the box that is closest to your viewpoint.

	Strongly agree	Agree	Disagree	Strongly disagree	Don't know or Not applicable
The clinic provides enough information about my HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I feel supported to self-manage my HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am involved in decisions about my HIV treatment and care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

D6 Here are some statements about your experience with your GP. Please tick the box that is closest to your viewpoint.

✓ Experience with care

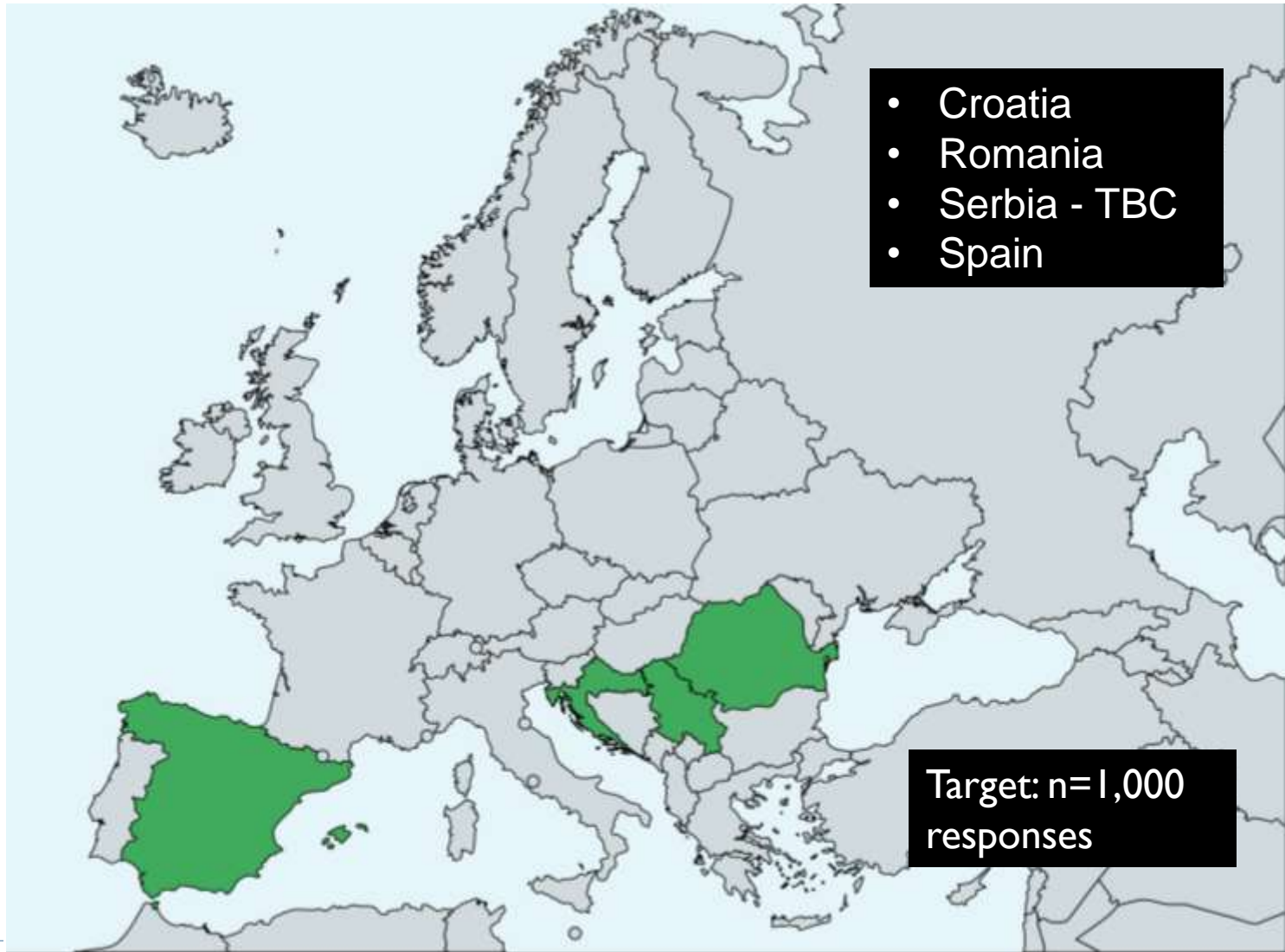
	Strongly agree	Agree	Disagree	Strongly disagree	Don't know or Not applicable
In my opinion, my GP knows enough about my HIV condition and treatment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am comfortable asking my GP questions about my HIV	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My GP is as involved as I want them to be with my HIV care	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
As far as I am aware, my HIV specialist and my GP communicate well regarding my health	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Key Methodological Decisions

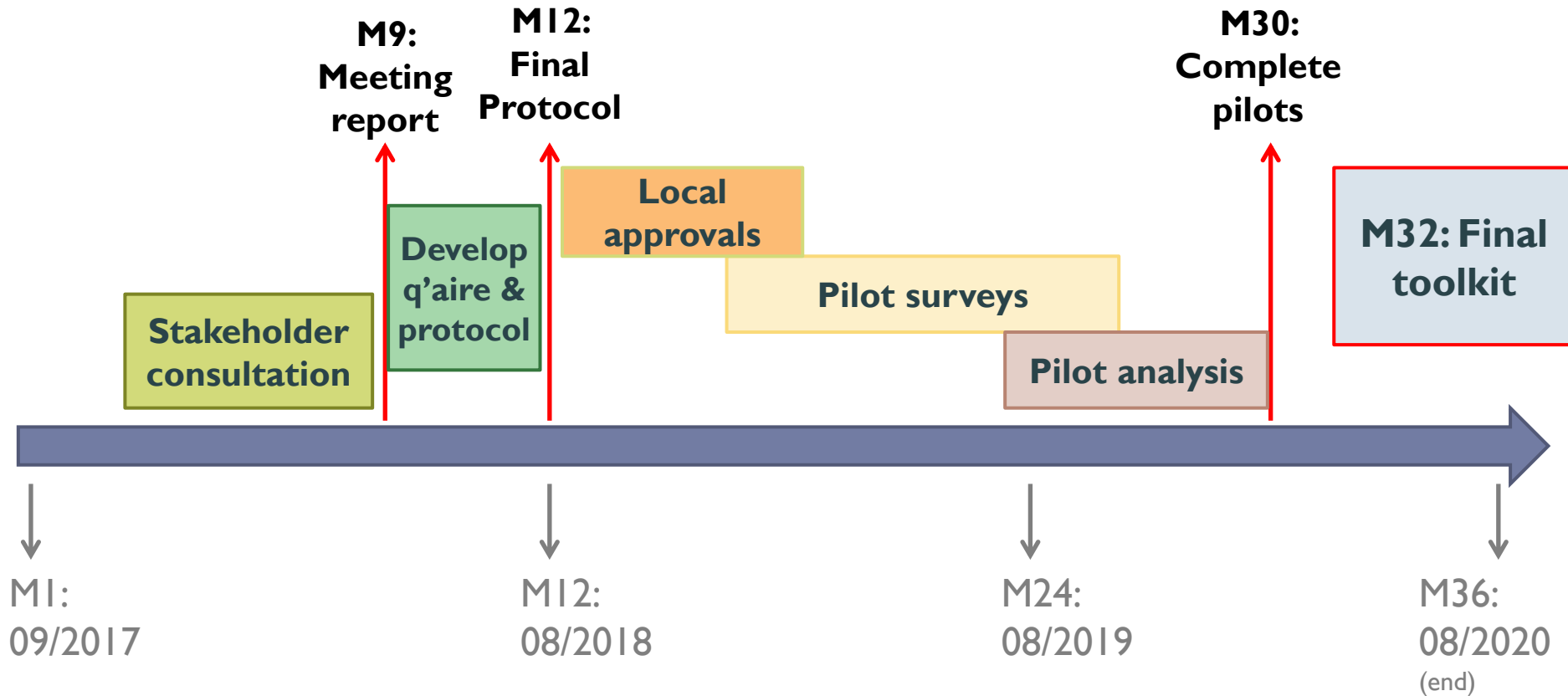
1. Questionnaire design
 - ✓ Topic areas, validated survey instruments, pre-testing
2. Target populations
 - ✓ HIV, Hepatitis, STI, TB → in which countries
3. Sampling method
 - ✓ Random sample vs convenience sample
4. Survey mode
 - ✓ Paper vs electronic (online, tablet, etc)
5. Recruitment method
 - ✓ Healthcare setting vs community vs online
6. Other
 - ✓ Length, incentive, etc



Pilot countries



Timeline and Milestones



Thank you